

**Quality of life of persons with complete traumatic spinal cord injuries in
Gaborone and surrounding areas; A Qualitative Enquiry**

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**Research assignment presented in partial fulfilment of the requirements for
the degree of Master of Human Rehabilitation Studies (by coursework)
in the Faculty of Medicine and Health Sciences
at Stellenbosch University.**



December 2017

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Abstract

Background: for persons surviving traumatic spinal cord injury, community reintegration is a multi-faceted challenge. While researchers here and there have explored the daily struggles and the lived experiences of discharged patients in different environments, more insights were needed in the given context.

The **purpose** of this study was to describe the individual experiences and quality of life of persons with traumatic spinal cord injury, after discharge from centre-based rehabilitation and returning to their homes in and around Gaborone, Botswana.

The **objectives** were to explore (1) the persons' individual experiences since returning home; (2) barriers and facilitators to participation in their homes and communities and (3) the persons' individual coping strategies

Method: A qualitative, phenomenological study design was applied. A pilot study was implemented to resolve practical and logistical challenges. Data were collected through home-based interviews and observations with a convenience sample of four participants, after discharge from the national rehabilitation centre following traumatic spinal cord injury. Thematic content analysis was applied to the transcriptions of the participants' responses; these were coded, grouped into categories and then into themes.

Findings: Six main themes covered: the impact of the spinal cord injury; access barriers; diverse experiences of government recognition and support; financial and insurance issues; family support and community responses; and individual coping strategies.

Conclusion: In the given context, there is a need for more, and deeper, direct engagement with, and decisive responses to, the needs and contributions of persons with spinal cord injury who have been discharged and who are endeavouring to re-integrate into their homes and communities. Implications and practical recommendations were identified for specific stakeholder groups.

Opsomming

Agtergrond: vir mense wat 'n rugmurgbesering oorleef het, is herintegrasie in hul gemeenskap 'n besonder komplekse uitdaging in die rehabilitasie proses. Terwyl etlike navorsers plaaslik en elders die geleefde ervarings van pasiënte wat ontslaan is in verskeie kontekste ondersoek het, was meer spesifieke insigte nodig in die gegewe konteks, in Botswana.

Die **doel** van hierdie studie was om die geleefde ervarings van mense met traumatiese rugmurg beserings na hul ontslag uit 'n rehabilitasie sentrum en hul terugkeer na hul tuistes in en om Gaborone in Botswana, te beskryf.

Die spesifieke **doelwitte** was om die volgende te verken: (1) die persone se individuele ervarings sedert hul ontslag en tuiskoms na hul rugmurg besering; (2) hindernisse en fasiliteerders van deelname in hul wonings en gemeenskappe en (3) die persoon se individuele hanteringstrategieë.

Metode: 'n Kwalitatiewe, fenomenologiese studie ontwerp is toegepas. Data is versamel deur middel van tuisgebaseerde onderhoude en waarnemings met 'n gerieflikheidsteekproef van vier deelnemers, wat almal vanuit die nasionale rehabilitasie sentrum ontslaan is na 'n traumatiese rugmurgbesering. 'n Loodsstudie is eers gedoen om enige praktiese of logistieke uitdagings op te los. 'n Tematiese inhoudsanalise is op die data transkripsies gedoen; gekodeer en in kategorieë gesorteer wat tot die temas bygedra het.

Bevindinge: Ses hooftemas het die volgende aangedui: die impak van die rugmurgbesering; hindernisse ten opsigte van toeganklikheid; verskeie ervarings van erkenning en ondersteuning; finansiële en versekerings kwessies; familie ondersteuning en reaksies van die gemeenskap; en hanterings strategieë (insluitend persoonlike geloof, selfaanvaarding, harde werk en toewyding.

Gevolgtrekkings: Daar is 'n behoefte aan meer, en dieper direkte betrokkenheid by die behoeftes en bydraes van mense met rugmurgbeserings wat ontslaan is en poog om te herintegreer in hulle gemeenskappe. Implikasies en praktiese voorstelle is geïdentifiseer vir spesifieke groepe belanghebbendes.

Declaration

By submitting this research assignment electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the authorship owner thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

December 2017

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Introduction

As an occupational therapist, I have been working at the only rehabilitation unit for patients with spinal cord injury (SCI) in Botswana with its nationwide catchment area for seven years. From clinical observations, especially during home visits following discharge, I have witnessed differences in the life experiences of persons with traumatic SCI in Botswana; sometimes as a result of differences in social, economic and other factors.

As a researcher, I was motivated to explore this situation further by home-based observations and in-depth interviews with persons with SCI themselves. The purpose of this study was therefore to document details of how persons with traumatic SCI live and cope at home and in their communities, in the hope that this might (a) help and empower other patients; (b) assist health and rehabilitation professionals in preparing persons with SCI better for community re-integration; (c) inform decision makers at diverse levels in identifying issues that need to be addressed to make service delivery more responsive to real needs and to (d) help generate future research questions.

The Context

Botswana is a land-locked country of 582 000 square kilometers and, with a population of 2 038 228 registered at the last census, it is one of the most sparsely populated countries in the world (Statistics Botswana 2011). Botswana has a unique history of progress and political stability. It is now classified as an upper-middle income country, after being one of the poorest countries in Africa, as recently as 50 years ago (World Bank 2016). However, poverty is high for a middle income country, despite extensive investment in social protection and measures to fight poverty (UNICEF Botswana 2011).

Social protection in Botswana: Botswana dedicates a substantial part of its gross domestic product (GDP) to social protection, making it one of the few countries in Africa to fully fund its own social protection programmes (World Bank & BIDPA 2013). While there are extensive statutory old-age, orphan and destitute benefits, there is no statutory benefit for permanent disability; only a means tested disability allowance (World Bank & BIDPA 2013)

The Motor Vehicle Accident (MVA) Fund, mandated by a National Government Act in 2007, provides compensation for “any person who is injured or dependants of any person who is killed in a road crash at any place in Botswana where the general public has access” (MVA Fund 2010: web reference). The extent to which persons with a SCI are covered by the MVA Fund is however determined by the police report which describes the cause of the accident and how it happened.

Due to the MVA fund, persons with a SCI caused by a road accident are thus generally in a better position economically than those with traumatic SCI from other causes (e.g. falls or assaults); but even they are supported to varying extents. The public health system officially provides for their medical needs (including technical aids etc.) but procurement protocols often mean long delays in actual provision.

While Botswana’s constitution prohibits any discrimination of persons on any grounds whatsoever, it does not make specific provision for the rights of persons with disabilities (Botswana Centre for Human Rights, 2014). Moreover, Botswana has not signed the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006). Other national legislations to protect the rights and promote equal opportunities of persons with disabilities in areas such as education and employment are also lacking (Botswana Centre for Human Rights, 2014).

Literature review

A basic literature review was implemented and related to the clinically observed situation in Botswana.

Spinal Cord Injury (SCI)

A spinal cord injury (SCI) is a medically complex and life disrupting injury, also associated with personal and psychosocial consequences (Angel et al. 2009; WHO 2013). Traumatic SCI comprises damage to the spinal cord due to traumas such as motor vehicle accidents, assaults or falls (WHO, 2013), while the causes of non-traumatic SCI can include infectious diseases, tumours, osteoarthritis or congenital impairments such as spina bifida (WHO 2013). SCI results

in a loss of mobility and other important functions such as bowel and bladder control, which in turn affect social life and may cause psychological distress (Dahlberg et al. 2004). SCI causes long term disabilities with complications that interrupt quality of life of affected persons and include mobility limitations, problems with social functions, psychological complications and/or medical complications (Collie 2009). Community re-integration comprises the ultimate goal – and simultaneously the biggest challenge – after traumatic SCI.

SCI severity is described according to the American Spinal Injury Association (ASIA) assessment tool which differentiates between complete and incomplete SCI (ASIA 2002; Dua 2012; Kirshblum *et al* 2011). Complete SCI involves a complete transection causing absence of sensory and motor function below the level of the injury, while incomplete SCI implies partial preservation of some sensory and/or motor function below the level of the injury (ASIA 2002; Kirshblum *et al* 2011; WHO 2013).

The **incidence** of new traumatic SCIs differs from one country to the other (Löfvenmark et al. 2014; WHO 2013). Research on SCI in Botswana *over time* is lacking and there is no definitive information on incidence across years. However, the recent study by Löfvenmark et al. (2014) indicates a high proportion of road traffic accident-related SCIs of the total number of traumatic SCIs (33 of 49 i.e. 68%) admitted to the national rehabilitation centre for SCI over the two year period 2011-2012. Other aetiologies of new traumatic SCIs recorded in Botswana include falls and assaults (Löfvenmark et al. 2014).

The overall **prevalence** of SCI has increased in high income countries as improving survival rates and life expectancy due to good health and rehabilitation services are noted (Middleton et al. 2012; Øderud 2014). In middle- and/or low-income countries, survival rates are generally poorer with pressure sores being a key contributor to post-SCI mortality (Gosselin & Coppotelli 2005; Øderud 2014; Visser, 2016; Zakrasek et al 2015). Moreover, pressure sores and their contributors (e.g. poor seating devices, support and/or poor personal care etc.) also reduce quality of life for persons with SCI (Øderud 2014; Visser, 2016; Zakrasek et al 2015). A study on surviving SCI in low income countries, conducted in neighbouring Zimbabwe, describes the impact of pressure wounds on morbidity and mortality after SCI (Øderud 2014). Earlier on, bladder-related infections and septicaemia were also identified as the cause of death for persons

with SCI in low income countries (Gosselin & Coppotelli 2005; Hoque et al. 1999; Øderud 2014).

As SCI rehabilitation inputs have increased with the application of a Swedish rehabilitation model and investments in Botswana, more patients are observed to survive and are living longer following traumatic SCI (Löfvenmark *et al* 2014; WHO 2013).

Rehabilitation after SCI

Rehabilitation is defined as a progressive, dynamic, goal-oriented process, which enables persons with impairment to identify and reach their optimal mental, physical, cognitive and/or social functional level (WHO 2001). The medical and rehabilitative management of persons with SCI aims to improve and optimize the residual function and to encourage participation in daily living (including livelihood activities) in a way that promotes most favourable quality of life for them (Mothabeng 2011).

In Botswana, the national SCI rehabilitation unit comprises a ‘rehabilitation chain’ meaning persons with a newly acquired SCI are admitted for emergency medical attention and stabilisation. They are then admitted in the orthopaedic or surgical wards until medically stable and then transferred to the unit for acute and active in-patient rehabilitation by a multidisciplinary team, including medical doctors; nursing, physiotherapy, occupational therapy and social work professionals as well as other consulting professionals like dietitians, psychiatrists and orthopaedic (spinal) surgeons. Rehabilitation is conducted according to a routine, in which patients are trained in activities of daily living (ADLs) such as bowel and bladder management; bathing; dressing and undressing; feeding and drinking and use of a wheelchair.

In the rehabilitation unit, the different professionals in the team also conduct information sessions to empower patients with knowledge about their different injuries and functional outcomes; the importance of rehabilitation; the patient’s resettlement; return to work; environmental assessments; bowel and bladder management and other medical issues regarding their injuries. Programs include home leave for patients nearing the end of their rehabilitation to facilitate their adaptation and coping capacity before being readmitted to finalise their

rehabilitation. Pending a home-, community and/or work-place assessment, they are then discharged.

The aim of all these activities, implemented with patients at the rehabilitation unit, is to contribute to a better quality of life of persons with SCI, but the process is often challenged by secondary complications including lack of (or limited) insurance; late readmissions due to transport logistics and/or family politics.

Outreach programs (including home based rehabilitation services) are limited due to shortage of staff. While general outreach by the Ministry of Health's air service is extensive, specific outreach to patients with SCI by air is limited as the combined opportunities are shared between departments. Thus, patients with SCI usually have to access services at the rehabilitation unit in Gaborone, using expensive private transport. Transport issues were already identified elsewhere as barriers to receiving medical and rehabilitation services (Silver et al 2012).

Economic impacts of SCI

Globally, SCI is reported to be costly and expenses include lengthy, acute hospitalization; medical equipment; consumable supplies; special transport needs; personal assistance and home and vehicle adaptations (Priebe et al. 2007; WHO 2013). Persons with traumatic SCI also experience complete or partial loss of wages and/or productive activities (Carpenter et al. 2007; Priebe et al 2007). One study with individuals with SCI returning to the community has indicated lack of insurance as a frequent barrier reported by participants themselves (Silver et al. 2012). Earlier studies also showed that insurance barriers often prevent persons with SCI from accessing the necessary, basic medical and rehabilitation resources (Boschen et al. 2003; O'Day et al. 2002).

Due to mobility and accessibility-based challenges, the economic prospects are often bleak depending on a number of factors (e.g. vulnerabilities on the basis of gender and disability). Disability affects household income and expenses as economic variables. Additionally the close link between poverty and disability and the gaps related to the consequences of economic vulnerability. Poverty, poor health and education, lack of access to employment increase

impairment while the limited infrastructure for access exposes persons with a disability, including SCI, to poverty thus a continued marginality in the economy.

In Botswana, clinical observations confirm that few persons with traumatic SCI return to work, yet most of these patients were breadwinners. Insurance cover for persons with SCI in Botswana differs widely between patients: from full insurance to medical and rehabilitation support only - depending on the details of the accident (e.g. whether the person was the driver responsible or a third party in another car).

Challenges facing persons with SCI

Once patients with SCI are medically stable and discharged from rehabilitation, they have to deal with the greatest challenge of all, which is to return home and eventually to community; to re-adapt to these settings, re-integrate into their communities, and participate and to carry on with their lives (Mothabeng 2011). Njoki et al (2007) identified a personal struggle to adjust to society and re-integrate, a lack of motivation and confidence as well as poor employment prospects as challenges facing youth with SCI, on discharge from rehabilitation in South Africa.

Issues of *subjective* quality of life are perceived by persons with SCI as including the ability to fulfill their roles as members of their households, participants in their communities and citizens of their world, which is the ultimate, aspired outcome of rehabilitation (Mothabeng 2011).

Clinical observations in Botswana confirm evidence from elsewhere (Bwanjugu & Rhoda 2012) that indicate long stays in hospital and in rehabilitation due to challenges such as secondary medical complications (e.g. pressure wounds), which delay the rehabilitation process. In the rehabilitation unit, patients with paraplegia are set for 10 weeks of rehabilitation, while a patient with tetraplegia is set for sixteen weeks. These periods, added to the original acute hospitalisation, mean a long time away from family, friends and their former lives. Compounded issues of adaptation, re-integration and participation have been observed.

Quality of Life

Far beyond the focus of SCI, rehabilitation professionals' quest to understand their patients' experiences in order to develop services that are responsive to the patients' needs has been ongoing for many years (WHO 2013). This culminated in the World Health Organisation's development of a *Quality of Life assessment instrument (WHOQOL)* according to which, quality of life is described as

"[...] an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health; psychological state; level of independence; social relationships; and their relationship to salient features of their environment." (World Health Organization 1997; no page reference given).

While the WHOQOL fulfils the need of gathering information both from the relevant health/rehabilitation professionals about patients, and from the patients themselves, the need remains to hear more from individuals with SCI in less-researched contexts (like Botswana) themselves. WHO (2013) reports that objective determiners of quality of life, including the accessibility and availability of quality technical aids (e.g. wheelchairs), are limited in developing countries like Botswana.

Quality of life appears to be influenced by factors such as the nature and severity of the impairment; medical complications; time since injury; age; sex; race; marital/relationship status; educational level; work; social participation and diverse environmental factors (Chang et al. 2012). Hammel (2007) recommended that quality of life is a crucial variable and should become the ultimate goal of rehabilitation, offering a platform to document the special effects of rehabilitation for persons with SCI.

Personal and environmental factors

Boredom and lack of purpose were reported to be challenges for persons with SCI in neighbouring Zimbabwe (Øderud 2014). In Botswana, there are no active support groups, sport

or recreation facilities or social games for persons with SCI: they only meet in the hospital as inpatients and have no other social activities that bring them together unless they are readmitted to the hospital/rehabilitation unit (Löfvenmark et al 2016).

Some persons with SCI in Botswana come from environments rife with barriers for persons with SCI in that they might not have a bathroom for bathing or bowel management; might have an inaccessible outside pit latrine toilet and coming from difficult terrain including deep, loose sand or loose stones (Löfvenmark et al 2016). Similar difficulties were described in Zimbabwe where persons with SCI feared returning to their home and community where things were not physically accessible for them (Øderud 2014).

Another challenge for persons following SCI is to deal with how community views and reacts towards them (WHO 1996; 2013). Community and family members will be anxious about them and may react with pity and by being too helpful to them (WHO 1996; 2013). After injury, relationships between patient, family and friends might be strained which might result in loneliness for persons with SCI (WHO 1996; 2013).

Having considered all this, I was interested in exploring these patients' subjectively described life experiences.

Underlying framework

The International Classification of Functioning, Disability and Health (ICF) provides a framework for describing and understanding disability (e.g. resulting from a SCI) in terms of body functions and structures; activity; and participation (WHO 2001). Problems or difficulties in these three components are conceptualized as impairments, activity limitations, and participation restrictions respectively (WHO 2001). Aspects of functioning and disability are thought to be affected by both health conditions as well as contextual factors, which in turn comprise personal and environmental factors (WHO 2001). Furthermore, impairments, activity limitations and participation restrictions have non-linear, complex relationships with each of these factors (WHO 2001); as indicated by the bi-directional, connecting arrows between all the elements in the framework, illustrated in Figure 1.

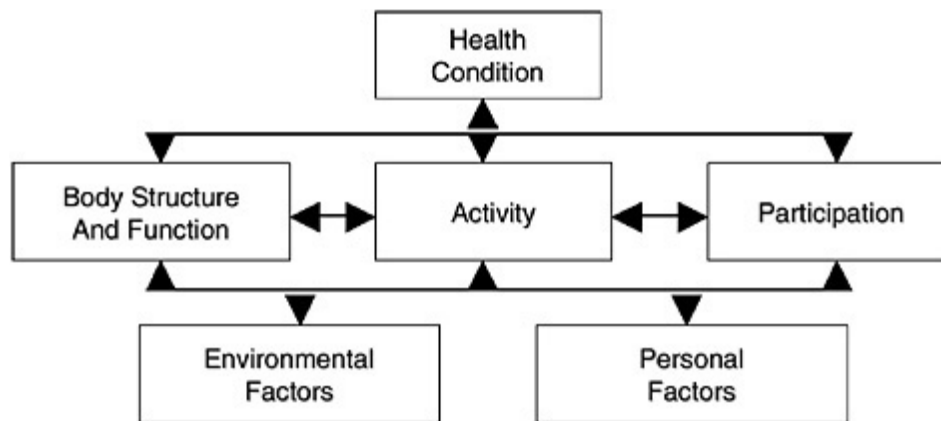


Figure 1: A schematic overview of the main elements of the ICF (WHO 2001).

The ICF embraces community reintegration within the bigger area of *participation* and it is further emphasized as the process in which persons with disabilities become part of the mainstream of their family and community life; being active and contributing in normal roles and responsibilities (Carpenter *et al* 2007). Participation is conceptualized broadly in activities of daily living and social roles acknowledged by the specific socio-cultural context (Noreau & Fougereyrollas 2000). The widely experienced consequences of SCI have been identified to interrupt participation in economic and family roles; domestic activities and productive activities; and recreational activities including participation in cultural events, sports, fitness and games etc. (Carpenter *et al* 2007). Satisfaction with life for persons with SCI has been documented when they are taking part in productive activities such as working, leisure and education (Cushman & Scherer 2002). These activities associated with life satisfaction for persons with SCI have long been emphasized as associated with community reintegration (Cushman & Scherer 2002; Fuhrer *et al.* 1992). In a study conducted by Carpenter *et al* (2007), participation in physical, social and other activities after a SCI was facilitated by environmental factors. This and other interactions between elements within the chosen ICF framework contributed to the focus of the small-scale study described here (which was completed for degree purposes in the context where I work as an occupational therapist).

The purpose of this study was thus to provide some answers to the research question, which was:

What are the life experiences of persons with complete traumatic spinal cord injuries (SCI) after discharge from hospital and returning to live in their homes in and around Gaborone, Botswana?

Due to its coverage of the complexity of the interrelating factors affecting persons with SCI, the ICF (WHO 2001) was applied as the conceptual framework, informing the design and the implementation of this study; and the analysis and interpretation of the findings.

Method

In order to answer the research question, the **main aim** of the study was to explore some of the experiences of persons living with complete, traumatic SCI in and around Gaborone, Botswana, as described by the persons with SCI themselves.

The **objectives** (or steps to achieve the main aim) were to explore, through home-based interviews and observations:

- the persons' own individual experiences since returning home after the SCI
- barriers and facilitators to participation in their homes and communities
- the persons' individual coping strategies

Study Design

A qualitative, phenomenological study design was applied. Qualitative research takes into consideration variables in their natural setting (Joubish et al. 2011); it also aims to unfold and clarify human experiences as they happen in people's lives (Polkinghorne 2005). A phenomenological approach gives voice to participants and requires the researcher to present participants' views in their own understanding (Carter et al. 2011).

Study setting

It is assumed that individuals' perceptions, their actions and ideas are inseparable from their context and so when conducting qualitative research, it is best for the researcher to work within the participants' natural setting (Hammell & Carpenter 2000). Moreover, the focus of the research question was on the participants' life experiences *at home* after the discharge from hospital. Therefore, within the broader historical, physical, geographical, economic and social

context of Botswana described earlier, the study was implemented through home visits to the homes of the participants, in and around the capital, Gaborone. Due to the limited timeframe and budget of this study for degree purposes, only homes within a 100km radius of Gaborone could be reached but these homes included rural, peri urban and/or urban contexts.

Homes visited varied from urban, institutional houses with un-adapted bathroom, to peri-urban, rented homes with water system toilets to rural thatch or tin roof homes with pit latrine toilets (and traditional tin bath, filled by bucket from a standpipe/tap in the yard). Urban terrain was mostly flat and surrounded by tarred roads, while roads in peri-urban and rural areas were mostly gravel/dirt, uneven, sandy roads and difficult to use, especially in the rainy season.

Study population, sampling and participants

The focus was on adults who had had a traumatic, complete spinal cord injury (SCI) and had returned to their homes after discharge from rehabilitation. The sample population was identified (with ethics approval and permissions) from the national rehabilitation centre's data base according to the following selection criteria:

Inclusion criteria

- males or females
- with complete spinal cord injury (SCI) as diagnosed by the use of the American Spinal Injury Association Impairment Scale
- persons with paraplegia or tetraplegia
- at least 18 years old (in order to be able to give informed consent)
- younger than 55 years (as this population would still have expectations regarding return to work and not easily consider early retirement as offered from 55)
- persons with full, limited or no insurance cover.
- have worked before injury or not worked.
- back in the community
- married, single or with a partner
- with any level of education

Exclusion Criteria

Persons were excluded if the following applied:

- Traumatic *brain* injury in addition to spinal cord injury because they will have a different experience including possible cognitive and/or communication impairments.
- Non-traumatic spinal cord injury because the onset and progression of these are so different to traumatic SCI and are beyond the scope of the rehabilitation unit where I work.
- Those patients with less than a year since the injury because I feel they are still "treated as patients", might not have explored life after spinal cord injury and more so that, a close eye from hospital or rehabilitation unit is still on them.
- In patients are also excluded because they have not had time to experience life with SCI in their community.

In this qualitative study, convenience sampling (Maxwell & Satake 2006) was applied as follows: all potential participants identified from the rehabilitation centre's data base, who met the selection criteria and who lived within a 100km travelling distance from Gaborone, were considered. An initial telephone call was attempted to inform individual, potential participants of the study, invite them to participate and obtain consent to visit them and to make logistical arrangements for such a home visit. Recruitment challenges included: lacking or outdated contact details in the data base; potential participants not being willing to be visited and/or to participate; and/or willingness to participate expressed, but unsuccessful attempts to make arrangements for an actual visit. Six interviews (2 pilot study and 4 main study) were completed in total. A seventh interview was aborted and no data from it used as the participant used abusive language, became aggressive (he had a gun) and withdrew his consent.

Description of participants:

The participants' data were de-identified with a pseudonym and demographic details, including their age (captured as date of birth), gender, marital status, cause of injury, date of the injury, educational level and profession (if relevant) were recorded in the consent form, at the beginning of the first interview. A summarised overview of the demographics of the two pilot and four main study participants is presented in Table 1.

Table 1: Overview of participant demographics and personal circumstances

Participant/pseudonym	Pilot Participant 1	Pilot Participant 2	Main Participant 'Messie'	Main Participant 'Isaka'	Main Participant 'Mbezuma'	Main Participant 'Groose'
Gender	Female	Male	Male	Male	Male	Male
Age	43 yrs.	40 yrs.	22 yrs.	31 yrs.	51 yrs.	48 yrs.
Marital Status	Single - not in relationship	Married	Single -not in a relationship.	Married	Married	Married
Family/ household composition	Has a caregiver	Stays with family	Stays with his Aunt	Stays with his wife & a child (in parent's yard)	Stays with family	Stays with family Has a caregiver.
Home: type, accessibility, alterations etc.	Institutional ¹ house 3 bedrooms Not adapted Bathroom (toilet and bathtub). A ramp erected.	Institutional house. 2 bedrooms Not adapted Bathroom. A ramp erected. Independent in ADL's	Renting two bed, staying with aunt; No ramps and house is inaccessible on wheelchair; bathroom not adapted. Independent in most ADL's	Given a two roomed house (in plan of self-contained house), no bathroom. Uses toilet in main house and a traditional bath	Bathroom not fitted, inaccessible Pit latrine, no shower. Very steep ramp erected due to landscape. Independent in ADL's.(Dependent on others to access the house)	Institutional house, three beds; inaccessible bathroom (toilet and bathtub); a ramp observed. Independent with few basic ADL's
Cause of SCI	Road Traffic Accident (RTA)	RTA	Stab wound	RTA	Fall from a house/roof	RTA
Time since SCI	6yrs	11 yrs.	2 yrs.	5 yrs.	3 yrs.	14 yrs.
Home context	Urban	Urban	Peri-urban	Peri-urban	Rural	Urban
Employment	Yes	Yes	Student	Unemployed	Yes-employment offered but not accessible	Yes
Insurance Yes/no	Yes	No- Old MVA Fund Act	No	Yes	No	No-Old MVA Fund Act
MVA fund yes/no	Unlimited Cover MVA-Fund	Government responsibility	Government responsibility	Limited Cover- MVA-Fund	Government responsibility	Government responsibility

Though some participants are termed government responsibility and some MVA Fund insurance, it has to be understood that all these participants receive most if not all the medical /rehabilitation in a government hospital but differ in situations such as if one has complications / need to be referred to private either locally or to South Africa and insured by MVA Fund can be referred to South Africa for further investigations. These are very rare occasions though to be referred to

¹ Institutional houses are ones built and let by the Botswana Housing Corporation (BHC) – they come in different sizes and levels of services included e.g. low-cost, medium-cost and high-cost.

South Africa. While those fully taken care of by the government are only referred to private hospitals for medical attention only in the country and do their rehabilitation in Botswana.

Pilot Study

In qualitative research, a pilot study is helpful in recognizing the barriers that might be encountered in the research process and to check and improve questionnaires, questions and/or interview practicalities used for data collection, (Jairat et al. 2000; Kim 2010). The core benefit of a pilot study is providing the researcher with the chance of making changes to avoid pitfalls, and to gather the richest data possible, in the main study (Kim 2010). It is also useful in increasing the trustworthiness of the research process (Kilanowski 2006; Kim 2010; Padgett 2008).

A pilot study was conducted with two persons, a man and a woman who met all the inclusion criteria. These pilot interviews lasted between one and two hours. Interviews were voice recorded and transcribed, but not analysed. The main focus for the pilot interviews was to assist in refining the interview questions and to assess the logistical details of the interviews (such as length of interview; audio recording quality etc.). Nothing needed to be changed after the piloting process.

Data collection

Data collection instruments: As in all qualitative studies, the researcher was the primary ‘instrument’ in data collection and analysis (Terre Blanche & Kelly 1999). As such I, the researcher, used my advantage of being bilingual (Setswana and English) and was able to offer the participants their choice of language for the interview. I was also carefully reflective of both my role as an occupational therapist - already known to some of the participants - and as a researcher, and tried to clarify this to the participants.

Based on the objectives of the study, a *semi-structured interview guide* comprising both closed and open-ended questions was developed in English. Basic principles of interview-questionnaire design and development were followed, including the avoidance of ambiguous, leading or loaded questions (McMillan & Schumacher 2001; O’Leary 2014). Once approved, the interview guide

was translated into Setswana, with a back translation into English for confirmation of the correctness and clarity of the language used (Appendices A & B in English and Setswana respectively). A printed copy in the participant's language of choice was used in each interview and additional, prompting questions were added where more information was needed or where it was felt that the participant could give even richer information if prompted. The interviews were all audio-taped, with the participants' consent.

Data collection strategies

These comprised interviews and environmental observations:

A semi-structured interview was conducted with each of the participants in their home environments following discharge (pending informed consent, see Appendices C and D). Follow up interviews/telephone calls were conducted in order to verify earlier responses that needed more explanation. Both the semi-structured main interviews and the follow-up telephone, interviews were audio-recorded (and transcribed) with the consent of the participants.

Environmental observations of the participants' home environments were captured in field notes and in photographs, by means of a digital pocket camera, with the participants' informed consent (Appendix E and F – in English and Setswana respectively).

Data management and analysis

Three stages of qualitative data analysis were followed, namely; data management, generating meaning and verification (Carter et al 2011).

In terms of ***data management***, audio taped interviews were transcribed word by word within a week, while each interview was still new in the researcher's memory; while writing observational field notes and reflective journaling occurred on the same day of the interview. These transcripts were anonymised (by using an alias or pseudonym, chosen by the participants themselves) and stored in a password protected computer. Paper copies were stored in a locked office cupboard, and all reading and analysis took place only in private, quiet spaces with due care taken to guard confidentiality.

In terms of ***generating meaning***, the transcripts were then repeatedly read so that I, the researcher, could immerse myself and become familiar with the data, and then analysed in order

to generate a coding system from which categories were developed. All these were done manually through the use of a colour coding system. Original documents of transcripts and observational notes were printed and colour coded according to a data driven (inductive) thematic analysis (Braun & Clarke 2006). Thematic analysis is described as “a method for identifying, analysing and reporting patterns (themes) within data. It minimally organizes and describes your data set in (rich) detail” (Braun & Clarke 2006: 79). All the data with the same coding colours were grouped together on posters in order to establish categories, which were then collated into potential themes.

In terms of **verification**, follow up telephone-interviews were conducted to confirm statements and to ascertain whether participants wanted to add or omit any information (Braun & Clarke 2006). Transcribed interviews were discussed with the participants for member checking and also for confirming the thematic coding system. A second researcher (the main supervisor) audited the data analysis, to check if the potential theme groupings’ worked in relation to the coded extracts (Braun & Clarke 2006) and to assist with the drawing of conclusions to determine whether findings from different sources were pointing in the same direction (Carter et al 2011).

Trustworthiness

The four criteria of trustworthiness (i.e. credibility, transferability, dependability and confirmability) aim to increase the authenticity of each aspect of the research process and outcomes (Denzin & Lincoln, 2003; Janesick, 2003; Schwandt 2001).

- **Credibility** refers to the agreement or ‘fit’ between the participants’ own views of their experiences and the researcher’s reconstruction or representation of these (Lincoln & Guba 1985; Schwandt 2001). This was achieved through the use of the participants’ verbatim responses, and through thorough member checking (Carter et al 2011) during the follow-up interviews.
- **Transferability** refers to the generalisability of the findings to other cases (Lincoln & Guba 1985; Schwandt 2001). While there was much diversity even *within* this small-scale study, the home-based interviews, observations and follow-up interviews in this study confirmed life experiences that echoed those found elsewhere in Botswana (Löfvenmark 2016) and in other developing country contexts, such as Zimbabwe (Øderud 2014). Furthermore, the home-based interviews, observations and follow-up interviews as a strategy are easily replicable – and

recommended – for other contexts.

- **Dependability** refers to the responsibility to ensure that the research processes are sound and documented in a way that can be traced and/or replicated (Lincoln & Guba 1985; Schwandt 2001). To fulfil this criterion, an audit trail of decisions and actions was compiled from field notes, recordings and transcripts.
- **Confirmability** refers to the need for the link between the researcher's assertions and the actual data to be clear and as objective as possible (Lincoln & Guba 1985; Schwandt 2001). Thus, I tried to include enough 'raw' data (participant responses) to enable the reader to see the links (Mays & Pope 2000). Moreover, member checking was done by means of a follow-up telephone call to all participants to ensure that the data was interpreted as closely as possible to the participants' meanings, and to ascertain whether they wanted to add or omit any information (Braun & Clarke, 2006). I also triangulated findings from the recorded interviews/transcripts, in-depth field notes and contextual photos taken (to visually present environmental barriers around the participant's home environment).

Ethical considerations

All research involving persons needs to meet the basic ethics core values of (a) respect for persons (incorporating the principles of autonomy and confidentiality); (b) best interest or wellbeing (including the principles of non-maleficence and beneficence) and (c) the principle of justice (Horn 2011; HPCSA 2008; WHO 2012). In this study, these principles were applied as follows:

- The principle of **autonomy** emphasizes that participants should be allowed to make choices and decisions freely based on what they prefer (Carter et al 2011; HPCSA 2008; Joubert & Ehrlich, 2007). The principle also emphasizes that those unable to make informed decisions and who are therefore vulnerable, should be protected (Carter et al 2011; HPCSA 2008; Joubert & Ehrlich, 2007). Autonomy was addressed through the implementation of informed consent and participants gave their permission to participate, after the study had been explained to them in their choice of either Setswana or English, both verbally and in writing (see Informed Consent Form, Appendix C (English) and D (Setswana)).

- A separate informed consent form was used regarding the taking of contextual/environmental photographs (to support observational notes on environmental facilitators and barriers). (See Appendices E and F for English and Setswana forms, respectively). All participants had a choice of the language they understood better (Setswana or English) and all necessary documents were read page by page with them in their chosen language.
- **Confidentiality** during the interviews was attained by requesting for a private place/room in a house to conduct interview, as a way to protect the privacy of the participants and their responses *during* the interview. After the interviews, only the researcher had access to the audio recording, the field notes and the supplementary photographs and these were then de-identified by using a pseudonym- or alias (rather than a numeric code) since I am dealing with qualitative data. All electronic data has been stored in a password-protected external hard-drive. Paper based data sources such as transcripts, field notes, contextual/environmental photos and recorded interviews have been stored in a lockable filing cabinet in my office, at my place of work with only me and my supervisor at work having a key each. Data will be stored and kept in a document bank for 10 years (DOH, 2015), with access possible by contacting the supervisor of the SCI unit or me.
- **Non-maleficence** requires researchers and health professionals not to cause any form of harm and avoid exposing others to unnecessary risk, (Carter et al 2011; HPCSA 2008). Some questions did evoke emotive experiences/memories of participants. Although arrangements had been made for support from the Social work/Psychology department to see these informants should such cases be experienced, I, as an occupational therapist trained in basic counselling and support, was sensitive and was able to provide immediate support and ensure that participants who did become emotional were not left unsupported. [Note: In the case of the potential participant who became angry/aggressive: I terminated his participation in the study and ensured his return to the SCI Unit, for support and assistance by the relevant professionals.]
- **Beneficence** means that as health professionals, we should act in the best interest of patients with the main focus of helping them and in a way that best promotes their welfare (Carter et al 2011). Exploring the participants' experiences of living with SCI

with them was considered to be more beneficial to them than causing harm. The research was intended for the benefit of patients with SCI in order to assist in development of more responsive services and policies. Researchers have a duty to make themselves accessible to participants (HPCSA 2008). This was honoured by planning all interviews to be conducted on weekends to give me, the researcher, the opportunity have time to engage longer if needed, in their comfort zones and also to save participants the energy to travel to hospital.

- **Justice** requires researchers to select and treat all potential research participants equally and fairly (Joubert & Ehrlich, 2007). In terms of having equal chances of being recruited (and thus one's voice being heard), the limited scope of this study restricted my travelling to Gaborone and its surrounds and prevented me from recruiting participants from further afield in Botswana. In terms of justice in language access, participants all had the choice of Setswana and/or English which are the two national languages of Botswana and this provided equal opportunity to express themselves in the language of their choice.
- **Approval and permission to conduct research;** the following processes were followed:
 - the study protocol was submitted to, and approved by, the Stellenbosch University Health Research Ethics Committee (Approval no.: S14/10/232: Appendix G).
 - the research was conducted in Botswana, therefore application for ethical approval and permission was submitted to, and granted by:
 - the Ministry of Health of Botswana (Approval Ref.: HPDME-13/18/1 Vol. IX (528) : Appendix H)
 - the Princess Marina Hospital Research Ethics Committee for permission to conduct the study using patients. (Approval Ref.: PMH 5/79 (192): Appendix I).
 - the Princess Marina Hospital Superintendent (Appendix J),
 - the relevant Heads of Departments (Orthopaedics and Psychology Departments. (Appendix K; a & b).

Findings

As described earlier, an inductive thematic analysis was applied (Braun & Clarke 2006), which led to the categories and six main themes; tabulated in Table 2 and described below.

Table 2: Tabulated overview of the six themes and the contributing categories.

Themes	Categories
<i>Theme 1: The accident brought my life to a standstill</i>	1.1 Emotional pain – and anger 1.2 Impacts on physical life 1.3 Impacts on occupation and/or livelihood 1.4 Impacts on family and social life
<i>Theme 2: Access is a problem</i>	2.1. Accessibility of the home environment 2.2. Transport 2.3 Access to public places
<i>Theme 3: We are not being recognised [but also:] Government is really trying</i>	3.1: Recognition of & consultation with PWD 3.2: Acknowledgement of government constraints 3.3: Service delivery end points
<i>Theme 4: Things can be so tough but you need money to fix one or two things and you can't get money</i>	4.1: Financial dependence 4.2: Work and productive activities 4.3: Insurance issues
<i>Theme 5: I won't sleep on an empty stomach when they are around.</i>	5.1: Returning home after discharge 5.2: Family support 5.2: Community responses
<i>Theme 6: I believe there is nothing that can be difficult for me</i>	6.1: Fulfilment of roles and responsibilities 6.2: Faith and (self-) acceptance 6.3: Capabilities, determination and hard work

Due to space constraints (word limits), only the English translations of participant responses are presented, except where the Setswana language version of the original response comprises a particular idiomatic or cultural element of interest or significance.

Theme 1: “*The accident brought my life to a standstill*”

The above response to interview question number 6: ‘How did the injury affect/ impact on your life?’ captures the first theme which describes the participants’ personal experiences of how they experienced living with the SCI in their homes and communities. These responses were coded in the following categories:

Category 1.1: Emotional pain – and anger

Feelings of pain were communicated in this category as one participant expressed his emotions towards situations he could not do much about.

- *I was so pained and had to give up as I am nothing in this life. The thing is when I got here I tried to be involved but hey...it's sad at times it's very sad (Goose)*

He also went on to describe the reality of the frustration and anger when encountering physical barriers and activity limitations:

- *Because there are times when you are sitting there, I am on a wheelchair, my wife is not around my boys are not around, maybe my wife just dashed to the main mall to get something. She has forgotten to place some water where I could easily access it and I am so thirsty. I would ask, what is this now? How do I get water in the fridge, how do I get water in the kitchen. I will be so angry. Sometime I will be angry with myself. (Goose)*

Category 1.2: Impacts on physical life

One participant also described physical pains:

- *I can say with regards to the injury...it's the pains that you will find haunting me, things like that. (Messie)*

Responses further indicated the physical limitations experienced:

- *Ah! Am no longer able to take myself outside where I want. (Goose)*
- *Things such as taking myself to the toilet are things that have changed. (Messie)*

Related to this:

- *It becomes very difficult to live without things such as catheters, uro bags because that forces me to use those that I have used so now it becomes unhygienic and I might be infected. (Messie)*

The impact of the SCI on bladder/bowel management thus was not only an issue of access and independence, but supply of needed consumables. Moreover, the cost and/or lack of access to these had further impacts on hygiene; health and infection (see also Theme 4).

Category 1.3: Impacts on occupation and/or livelihood

The wider concept of occupation (i.e. employment or other income-generating activities and/or regular life-stage activity such as education for a younger person etc.) comprised this category, characterised by this quote:

- *It affected the fact that am no longer having my business, am no longer able to do anything for myself... My life is stagnant. I woke up to wait for ... requesting charity.(Isaka)*

The occupation of pursuing education was also halted for one participant who was still at school:

- *I got injured when I was still pursuing my studies and from there I couldn't continue with my studies... (Groose)*

Furthermore, plans, hopes and dreams relating to future occupation and activities were shattered:

- *My interests were to be a farmer. I was a person who wished to purchase a tractor [...] then plough, and be a farmer.(Mbezuma)*
- *I was interested in volley ball. I coached volley ball...I grew up being a volley ball, I slept volley ball, I dreamed volley ball... Yah! Before I got injured I was one of the top volley ball players in the country, I played volley ball for the National Team from 1998 to 2001.(Groose)*

The hopes and dreams of the participants were thus realistic and achievable until the traumatic SCI.

Category 1.4: Impacts on family and social life

- *Before my injury I lived my life to the fullest. I would take my family out for camping, I used to like camping... I had a lot of friends before I got injured and some of them are non-existent today.(Groose)*

The losses in this category thus covered both family activities and social relationships.

Theme 2: “Access is a problem”

The statement ‘Access is a problem’ was used by all participants in describing their experiences on issues of accessibility in their homes, their communities; access to transport and/or other environmental challenges;

Category 2.1: Accessibility of the home environment

Observations of the home environments included that institutional or government subsidised houses seem not adapted but are only fitted with ramps to access the house in and out. Another observation is that rented house not done adaptations at all. While those who owned and stayed in their houses has some sort of adaptation done to their houses.

Accessibility of the home environment was experienced variably by the participants ranging from good accessibility within the home; to needing some assistance outside the house; to complete inaccessibility:

- *I call kids to push my wheelchair. My house is built on a higher surface as you can see. I am not able to push this wheelchair by myself up the ramp, (Mbezuma).*

The inaccessibility of one participant's cattle post² and fields, were also described by the participant who could still drive his car to his cattle post but then could not get around when he was there due to the rough terrain and so he stopped going at all:

- *Currently I'm not able to perform a lot of things ... I can go to the cattle post sometimes but now I know am not able to access the cattle post so I will be forced to stay home. Now I don't go because I know I will stay in the car, (Isaka).*

The challenges of the participants' neighbourhoods were also described, for example:

- *Roads are so bad my sister... it would have rained like this... to me it's a challenge that I can't use any route. Our roads have where you find small streams filled with water, there I have to pass and if I have to pass but I have no idea how deep this water is; then if you avoid this stream of water then you go on rocks which blocked the road, they have potholes and it's a problem... (Goose).*
- *This side of the community is rocky, it has small streams and it is sandy, (Isaka).*

Another participant went on to highlight the dependence upon others, and moreover the problem of availability of help to access places in his immediate neighbourhood:

- *When the school is closed, I call small school-going boys who will then pull me, (Mbezuma).*

Category 2.2: Transport

While one participant had been able to continue driving his car, public transport was a major barrier to the other participants:

- *It's very difficult to access busses ... specially on wheelchair it is very, difficult to access transport so this was one thing which was mentioned in disability Pitso³;*

² A family's cattle post is usually located at a water source some way outside the village, where hired cowherds are usually responsible for the cattle, monitored by the cattle owner. Owning and monitoring one's cattle are an important aspect of one's livelihood and identity.

transport needs to change so that we allow people with disabilities those on wheelchair to get into busses and all that... and then combis [minibus taxis]...if I want to go to Game City [a big shopping mall that is wheelchair friendly if he can get there], I can't go there, (Goose)

Category 2.3: Access to public places

Participants' responses indicated challenges in accessing point-of-service stations such as police stations, clinics, government offices and also shopping malls etc. which in turn hinder participation.

- *in few places, roads are troubling there and there; you find that there is where I am not able to cross, then I will take long route to turn, (Isaka).*

The widely experienced need to do long detours due to few points being accessible by wheelchairs, was detailed by *Goose*, outlining the challenges in getting in and out of the main mall by wheelchair :

- *It's terrible, sometimes I will sit here trying to think of going to main mall and okay I will go to the main mall. What do I do at the main mall? I can only enter the post office ... Entry points? There is one at the bank, sometimes you get there and they have parked in front of that entrance, so you can't go through the bank one. So if you miss that one, you go to the next one... There is some security guys who like parking there also. So they also like blocking it. So if you find that one blocked, you go behind Barclays Bank. There is another entrance there. But don't trust that one... [Researcher: Why?]: Because it is always blocked. You hardly use that one. Then there is another one at the filling station... At least that one, I have never encountered a problem of blockage because they will clamp the vehicles if they block that space. It's far but if I want to go to the main mall then I have to go as far as that one [pause] and sometimes you go in and all the places are closed, you want to come home. What do you do? You go back to the filling station. That will be the only exit point, (Goose).*

³ A 'Pitso' (Setswana, meaning a 'call') or consultative forum, organised by different Botswana Government departments, for different purposes to enable the public to be part of policy planning, monitoring and implementation. The *Pitso* referred to here, was one specifically aimed at dealing with issues faced by persons with disabilities (<http://www.gov.bw/Ministries--Authorities/Ministries/State-President/Office-of-the-President/Divisions/Office-of-People-with-Disabilities/>)

His responses, repeating some of the others' frustrations, thus indicated a combination of physical barriers (few access points that are flat/smooth/level or wide enough for a wheelchair to pass) as well as lack of consideration by persons parking and blocking the entry points that would be structurally accessible. Well-implemented parking laws at one place (i.e. transgressing drivers' vehicles being clamped and released only upon payment of a traffic fine) were identified as being a help or facilitator. The frustration of repeatedly finding access points blocked or closed was clear.

The differences between older (less accessible) and newer (more easily accessible) buildings were also raised:

- *Shops are okay but old shops in the main mall is a problem....some shops which are newly built in malls like Game City and Rail Park [= two newer shopping malls]...I can independently access Rail Park. There you can see that we have been catered for. When you get in their toilet you can see that they knew that there are persons with disabilities in this country but I talk about Gaborone Rank [= taxi rank and shops]; we have been excluded..., (Mbezuma).*

A response that encapsulated the complexity of access limitations was the following:

- *I thought what kind of life is this that I can't access things like facilities for interviews? (Groose).*

The physical access barrier here prevented this participant from being able to attend an interview for an employment opportunity, even though the employment itself would have been accessible. This also resonates with the earlier example of the cattle owner being able to drive himself *to* his cattle post, but then not able to move about and go about his livelihood activities once there. The *multi-faceted* impact of traumatic SCI upon the physical access and the resultant activity limitations and participation restrictions for these individuals was thus illustrated.

Theme 3: “We are not being recognised” but also: “Government is really trying”

This theme includes the *divergent* experiences and views of participants of the government's recognition of disability through policies and frameworks relating to persons with disabilities,

and the implementation status of these through service delivery systems in general and by specific public servants. This variability was sometimes expressed by one and the same participant (i.e. individual experiences of *both* extremes).

Category 3.1: Recognition of and consultation with persons with disabilities

This category describes the situations reflecting recognition and inclusive consultation (or lack of it) in which persons with disabilities – including traumatic SCI - find themselves.

-you know, disability in Botswana though we have an office at Office of the President personally I feel.....we are not being recognized, (Groose)

Furthermore, the frustration of not being heard was described vividly:

- *I attended a two day Pitso and I was disappointed because a lot of speakers at the Pitso were people with no disability. A lot of questions were taken from people with no disability. I had drafted a few questions to ask, I left there with my arms swollen because my hand was always in the air for the two days I was never picked ...*
Our voice is still not being heard because most of these disability organizations are being run by people without disability, so I always tell you will try to represent me you will not be representing me.
For us to say this is a proper consultation for people with disabilities we need to be seen in those committees.
I feel somebody with a disability should be in those committees, (Groose).

Concerns were also raised in linking their dissatisfaction with services because persons with disabilities are underrepresented in the Office of the President, Disability Office.

- *I don't think we have the right people because at National Office, the only person that I know who has disability is [name] and all people around him, are not persons with disabilities, (Groose)*

Other participants agreed that they are misrepresented by able bodied persons in trying to communicate their challenges.

Category 3.2: Acknowledgement of government constraints:

Factors such as government budget and government financial constraints were described in different ways and some participants expressed understanding and appreciation:

- *There are things they want to do for us but they can't do them because of financial constraints. The budget is very, very tight, (Groose).*

Groose went on to express that though he might want things done, he understands that the government is faced with a tight budget

- *...government is really trying, (Groose).*

Category 3.3: Service delivery end points

While appreciating some policies and systems, some officers' attitudes were among the greatest challenges faced in their communities in receiving government services, for example;

- *Government is trying its best but the people who have been put there [in the offices]; I think they are the ones who are disappointing us, (Groose).*

Theme 4: "...things can be so tough but you need money to fix one or two things and you can't get money"

In addition to the reduction or complete loss of a source of income or a livelihood, all participants raised the issue of costs related to living with a SCI; for example, costs related to wheelchair parts and maintenance; catheters and other consumables and increased transportation costs (when travelling with a wheelchair) for hospital visits etc.

Category 4.1: Financial dependence

- *But for me to go to the hospital - it's a lot of money... I haven't had any source of income; it's sometimes my parents when they offer me something, (Messie).*
- *It has affected me that I no longer have my business; I no longer manage to do anything for myself. At the moment I survive by asking and it had left me in debts: 'Ke bereka ka go kopa' - I always ask for charity, "please help me" because I no longer fend for myself to clear my credit, (Isaka).*

The literal translation of 'Ke bereka ka go kopa' is 'I work by asking/begging (for charity).

[Note: Exploring further the view of begging/asking as an 'occupation' was beyond the scope of this study].

- *Woo! What can you do, for me to move from point A to point B I need the wheelchair and without the wheelchair I can't go to work. So what do I do, I go to the bank and ask for a small loan, get a loan and go buy wheelchair parts and I continue that way, (Groose).*

For participation in employment, he was therefore caught in a vicious cycle and had to continue to get bank loans to be able to maintain his wheelchair to be able to continue working.

[Footnote: His need was referred back to the rehabilitation unit at this time and he was subsequently re-assessed and a more appropriate wheelchair provided].

Category 4.2: Work and productive activities

Though appreciating his employment, *Mbezuma* voiced frustrations about being under-utilised with reduced opportunities for productive activities (or lack of them) *in* the employment situation.

- *At work, I go every morning, to mark myself present but they don't use me and that means nothing to me. It's just that I don't know what doubts they have of what I can do for them.*
- Eh! I never changed my work and I told them even the Doctor compiled a report for them and highlighted my capabilities. They also see at work that I drive from Mochudi to Gaborone to report to work and back home. They can see I use a car. I don't know why they think I can't drive a Council car. It's up to them if they don't use me, (Mbezuma).*

Accessibility challenges were seen as the cause for not participating in functional activities contributing to a promotion in the workplace hence with a negative impact on financial status, for example

- *Because when people were writing interviews, access to the interview halls was non-existent so I couldn't sit for interviews, (Groose).*

4.3 Insurance issues

In this category some participants expressed their views on having - or lacking - insurance and how it affects their lives as people who live with SCI and as wheelchairs users.

On the one hand, those **with insurance** appreciated the assistance (e.g. *Isaka*) – but also described limitations regarding the coverage of only a few basic health and technical items, not the ones that the participants felt they needed:

- *They help me with the things I use (technical aids). They are not assisting in those that I need. My assistance from them is limited...*

At the moment my wheelchair is unable to mobilize in the field but when I ask for the one that can, they refuse to help me. [* the field where he could engage in productive activity if he had access to it]*

- *The reason they give me [for refusing a need] is that my account is limited, (Isaka).*

On the other hand, those **without insurance** described some of their struggles. These included the dependence on the general government or public health system to provide technical aids and supplies etc. and which in turn meant limited or lacking availability of supplies and long waits;

- *...ah, it's only to cry to the Government, there is nothing much I can do, (Messie).*
- *It's really affecting me because when you need something now you will get it after a long time, you finish crying, you finish, (Messie).*
- *I am not covered by MVA so anything I need to do on this wheelchair I need to pay for it, (Groose).*

Theme 5: I won't sleep on an empty stomach when they are around.

Both barriers and facilitators were identified in terms of family and community re-integration after discharge. Support from family and/or friends was described by participants as a very strong gear that takes them through the life challenges they experience in daily living.

Category 5.1: Returning home after discharge

Discharge and the return home is always keenly longed for and appreciated, and yet the transition brings with it other challenges:

- *I was happy that I was going home, but when I got home I was faced with different challenges to those of the hospital because in the hospital it was paved and ... so the wheelchair doesn't encounter challenges it just moves smoothly,*
- *I was living with people of the same situation in the hospital but going out there...is different, (Mbezuma).*

On the other side family support made going home post SCI and post hospitalization easier:

- *When I got discharged, I think because of the support from my wife I think everything went well very smooth. So transition from being whatever they term normal to disability well it was there I felt it then but the transition was very smooth because of the support I got from my family, (Groose).*

Beyond smoothing the transition after discharge, the support of people who care about them at home was repeatedly emphasised, as seen in category 5.2 examples below.

Category 5.2: Family Support:

In this category, participants described how the family is an encouragement in their lives and gives energy that allows them to participate in their roles and their everyday life:

- *Like I said in the beginning...I get a lot of support from my wife...she is the husband of this house. She is the mother of this house, she is my colleague, and she is my spouse. She is almost everything..., (Groose).*

Groose thus identified the role of a spouse (wife) as a strong support; and also the closest family in the home; including the response that determined the Theme 7 heading:

- *Family, when it comes to people you live with, those people who brought you on this earth they will not desert you...**I won't sleep on an empty stomach when they are around***
- *I live my everyday life because I live with people who never give up on me so that pushes me not to give up too (Messie).*

The kinds of family support received and described therefore span the range from material provision (no 'empty stomach') to physical and emotional support and moreover, love.

Category 5.2: Community responses

This category comprised both negative and positive experiences in terms of community responses to the participants, as persons living with SCI in their community. An example of underestimating the PWD included:

- *When I am with my wife, in town or main mall, people who know us, they tend to say, 'Dumela Mma' [= Good day, Mrs. - talking to wife]...eh how is he?' It's like I ... maybe I look so terribly ill that people can't ask me 'how are you?' (Groose).*

However, there were also negative reactions when a participant wheelchair user did not fit community members' preconceived or stereotyped expectations such as thinking he was faking being a wheelchair user when they see him well presented and having been rehabilitated and capable:

- *They underestimate wheelchair users as they are well known for wearing torn and untidy clothes; so now they see me well-kept and think I'm faking to use a wheelchair (Messie).*

- *Well when I first started going out, people seeing me not in bed at [= name of hospital], you know eish! There is a lot of teaching that we need to do especially to our fellow country men and women, (Groose).*

In all of the above examples, community has been described as lacking knowledge on the functional outcome post SCI injury or general lack of understanding of issues for PWD, as the community associated them only with hospital.

Overlapping with this medical or impairment focused view of disability, were the following responses:

- *Mmmh, Batswana⁴ are compassionate, just and caring people, (Isaka).*
- *Ah! People are willing to help when they see a person on a wheelchair..., (Messie).*

Such appreciation of what were seen as positive community responses was thus also expressed.

Theme 6: “I believe there is nothing that can be difficult for me”

The common denominator in this theme was the realisation of the participants of their own strength and agency in moving on in their lives post-SCI.

Category 6.1: Fulfilment of roles and responsibilities

The participants’ roles as a father, a husband, a brother and/or head of the family and/or a contributing member of the household were described in terms of the family’s respect, and the participant’s role to provide and/or contribute in the family, for example:

- *The respect they gave me when I was still on my two legs is still there, (Groose).*
- *No, all these fire woods they are fetched by me. There is no water in the yard, yet there is no one who is able bodied who goes to fetch water. The person who brings water is **the one without legs** (laughing), (Mbezuma).*
- *My assistance at home is to provide love. My assistance at home is to bring the mind of guidance. My assistance at home is to promise my capabilities. My assistance is to show that there is still life even if injured, (Isaka).*
- *I manage because I applied that training [= SCI rehabilitation programme] in my functional life; I manage; I can fend for myself even alone at home, (Messie)*

⁴ The people of the country of Botswana are called Batswana, which is the plural form of the noun **Motswana** (= a citizen of Botswana). **Setswana** as the national language.

However, some family members were scared that if the person with the SCI continues with regular activities, that person will hurt themselves, as expressed below:

- *They never allow me to get into the kitchen to prepare something to eat as they feel I will burn myself ... Sometimes when I cook, left alone ... and when they come they will shout at me telling me that I will burn myself, (Messie).*

Thus, the participants presented varied experiences in terms of identifying with and fulfilling their pre-SCI roles and responsibilities in the family and community on the one hand – and on the other hand being prevented by their families from being functionally independent.

Category 6.2: Faith and (self-) acceptance

Participants' faith in God as a support in daily life post-SCI was clearly expressed:

- *Is to go to church, you are always given words of encouragement. It also makes you feel there is a worth in living and others like having a positive mind, (Messie).*
- *We decided to give our lives to GOD and whatever we do, we sit down with our two boys and we pray, (Groose).*

Related to faith were the insights about the importance of self-acceptance of their situation as it helps them to pave the way forward in living with SCI:

- *It helps to accept because you focus on trying to do the best out of it. When you haven't accepted yourself you will not be able to think forward on ways to help yourself... Self-acceptance helps because I don't look back when I want to try to think forward. What can I do if I am saying 'hey I got injured and let me wait for handouts because I'm disabled? (Messie).*

Messie became very philosophical:

- *Life depends on how you face it (Messie).*
- *Positive life comes from [point number] one; accepting that you are now different from the person that you used to be and we have a quite a number of limitations, Point number two: for you to be able to succeed in life or to move forward in your life you need people around you to support you... (Groose).*

Thus acceptance of self and one's role in family was one of the positive factors that enable them to perform their roles – but as a person with a SCI. The acceptance and fulfilment of **new** roles was also raised:

- *I want to be an independent person; I want to have my own place and do things for myself. It's because I am a person who wants to make a difference with the life I'm living now so that other injured persons could realize that it's not the end of life facing these things (Messie).*

Category 6.3: Capabilities, determination and hard work

This category comprises a range of experiences that are difficult to separate: the participants' recognition of their capabilities after the SCI and the development of these through determination and sheer hard work:

- *For the things that are difficult; I try so that when I failed then I would have tried first, It's just that I don't want to lazy around and say I am disabled. No! No! (Mbezuma).*

An indication of the participant's dedication and hard work in provision for their families regardless of their disability:

- *It's me who brings water and fire woods for able bodied persons. At the moment we don't have water, pipes are dry. I hook a car trailer then load water containers ... When I go to the cattle post, I hook a trailer and I come with fire woods (Mbezuma).*

These expressions also echo pride in performing activities that are usually performed by able bodied persons in their families.

Some participants have a feeling that disability for them was a lesson equipping them with the driving force to actively engage in their functional life;

- *I don't know, it's just that disability would teach you the things you didn't have/know... (Mbezuma).*
- *You can find me having cooked...and like pushing my wheelchair; my friends know that they only push where it's difficult (Messie).*

These then were the six themes (and their contributing categories), as identified by means of inductive, data driven thematic analysis (Braun & Clarke 2006).

Discussion

The findings, presented above in the participants' own words, mostly speak for themselves (Lipenga 2014). A tabulated overview of how these findings (categorised and grouped into six

themes) linked back to the study aim and objectives (Table 3), is followed by a discussion on how they related to earlier evidence; and to the chosen framework of the ICF (WHO 2001).

Table 3: Overview of the themes identified from the data and how they related to the aim and objectives of the study.

Main Aim	Objectives (or steps to achieve the main aim)	Themes identified from the participants' responses
To explore some of the experiences of persons living with complete, traumatic SCI, as described by the persons with SCI themselves	1: To explore/describe the persons' own individual experiences since returning home after the SCI	<p><u>Theme 1: The accident brought my life to a standstill</u></p> <p>1.1 Emotional pain – and anger</p> <p>1.2 Impacts on physical life</p> <p>1.3 Impacts on occupation and/or livelihood</p> <p>1.4 Impacts on family and social life</p> <p><u>Theme 5: I won't sleep on an empty stomach when they are around.</u></p> <p>5.1: Returning home after discharge</p>
	2: To explore/describe barriers and facilitators to participation in their homes and communities	<p><u>Barriers:</u></p> <p><u>Theme 2: Access is a problem</u></p> <p>2.1. Accessibility of the home environment</p> <p>2.2. Transport</p> <p>2.3 Access to public places</p> <p><u>Theme 3: We are not being recognised [but also:] Government is really trying</u></p> <p>3.1: Recognition of & consultation with PWD</p> <p>3.2: Acknowledgement of government constraints</p> <p>3.3: Service delivery end points</p> <p><u>Theme 4: Things can be so tough but you need money to fix one or two things and you can't get money</u></p> <p>4.1: Financial dependence</p> <p>4.2: Work and productive activities</p> <p>4.3: Insurance issues</p> <p><u>Facilitators:</u></p> <p><u>Theme 5: I won't sleep on an empty stomach when they are around.</u></p> <p>5.2: Family support</p> <p>5.3: Community responses</p> <p><u>Theme 6:</u></p> <p><u>I believe there is nothing that can be difficult for me</u></p> <p>6.1: Fulfilment of roles and responsibilities</p>
	3: To explore/describe the persons' individual coping strategies	<p><u>Theme 6:</u></p> <p><u>I believe there is nothing that can be difficult for me</u></p> <p>6.1: Fulfilment of roles and responsibilities</p> <p>6.2: Faith and (self-) acceptance</p> <p>6.3: Capabilities, determination and hard work</p>

Experience since returning home after the SCI:

The realisation of the first objective ('to explore/describe the persons' own individual experiences since returning home after the SCI') was captured by the quote that became the

header of Theme 1 ‘*The accident brought my life to a standstill*’. Participants’ responses confirmed earlier evidence that their complete, traumatic SCI was a major life disrupting injury with physical, psychological, economic and social consequences; and with impacts in one area triggering impacts in other areas (Angel et al. 2009; Dijkers 2005; Kennedy et al. 2010; WHO 2013). Yet there were also positive experiences and responses of happiness and thankfulness.

Being described as a ‘*person who doesn’t have legs*’ summed up the physical impact in participants with para-, tetra- or quadriplegia (as per ASIA 2002) and who were now wheelchair users. The well-documented impact of complete, traumatic SCI on body structure and function includes loss of mobility and other important functions such as bowel and bladder control which may in turn effect a reduction in social participation and cause psychological distress (Collie 2009; Dahlberg et al 2004; WHO 2013). Furthermore, the interaction of all these impacts further compounded by the financial burden of unaffordable catheters, was described here as a vicious cycle of re-using such consumable products, with resultant risks of infection and thus worsening the physical condition.

The economic impact of the SCI was highlighted as participants lost their previous employment and/or independent income-generating activities and were now ‘*dependent on charity*’ and no longer able to provide for themselves or their families. Confirming earlier evidence (Kennedy et al 2010) participants here spoke of the change of one’s life style. Some spoke of not being able to participate in activities they used to perform pre injury such as income generating activities like agriculture and leisure activities (the economic impact of the SCI is further unpacked further down, in the sub-section on barriers to participation)

The emotional/psychological impact of the change from living their lives to the fullest before the injury, to losing that, was expressed in pain and anger and on the positive side, acceptance in due course. Some however, viewed the impact of the traumatic SCI as not having diverted their life that much and concluded that life is dependent on the way in which an individual perceives it.

According to Löfvenmark *et al* (2014), stressful emotions were mentioned as informants felt rejected, pitied and some were angry too. Different emotions by participants here were described and sounded to have been caused by issues such as isolation and sadness as this injury had

caused them more pain and described themselves as nothing in the community. Yet, some participants had learned to be thankful despite what had happened and considered factors such as still being alive and being lucky to be still employed as facilitators making them to be thankful.

Despite all the impacts that participants mentioned to be experiencing since they got injured, some of them indicated that they never imagined themselves to be disabled and mentioned not treating themselves as disabled persons. Others related themselves to being disabled, which was understood to be purely due to not being functionally independent in their life management as they have related themselves. Having a disability was noted by some participants as an opportunity to learn survival skills and personal strengths they did not know they had before and this insight became a coping strategy (revisited later).

There was also the perception that having the injury meant one door was closed, and to open other doors of good living for them they mentioned now being able to plan their lives better. Some though stated that for them they felt that the life one lives with SCI, is dependent on the way they perceive it regardless of having such a traumatic injury. These were some of the factors considered keeping some of the participants going on in their daily lives. Within the ICF framework, the construct of participation includes issues of being active and taking part in meaningful activities; making choices and taking control and having access to similar opportunities like other persons without disabilities from that social, economic and geographic environment (Hammel et al 2008; Heinemann et al 2013). While Carpenter *et al* (2007), agreed that participation in physical and social activities was profoundly impacted by the level of the injury of SCI as well as environmental factors, active engagement in life has been described as highly subjective (Cushman & Scherer 2002).

Barriers and facilitators to participation in the home and in the community

In a South African context, Mothabeng (2011) summed up the greatest challenge faced by persons with traumatic SCI returning to their homes and communities after long hospitalisation and rehabilitation; and that is that they are expected to participate and carry on with their lives. The second study objective was thus to explore and describe some of the barriers and facilitators

to participation in their homes and communities. This was achieved by several confirmations of, and some additions to, existing research evidence on barriers and facilitators to participation.

Barriers:

In their recent study in the same context, Löfvenmark *et al* (2016) described physical access barriers and inaccessibility in low and middle countries due to harsh and difficult terrain, and had highlighted issues of access in the homes and old malls as a major challenge for informants. Interviewed participants here confirmed and emphasised challenges they are faced with in the environment including a steep access ramp at the house, enforcing dependence on the assistance of other family members to be pushed in and out of the house; uneven terrain and sandy environments in important places such as one participant's cattle post. Roads were blamed by some participants with regards to accessing their communities. On the other side some participants had indicated not having any issues with accessibility in their home.

Access in the old malls was condemned by some interviewed participants as shops were built in a way that does not accommodate persons using wheelchairs while some praised the wheelchair accessibility in newly built malls (– *'I can independently access Rail Park [mall]. There you can see that we have been catered for'*).

One interviewed participant related physical access barriers for not being promoted in the workplace; as the interviews were conducted in inaccessible government buildings, even though he would have been able to access the actual work place. Lack of infrastructural adaptation for persons using wheelchairs was also hindering those performing their alternative (agricultural) income generation. Participants noted several factors hindering them in participating in their work and raised issues such as inaccessibility due to structural and weather conditions resulting in poor drainage hence not able to leave their houses when it rained.

Poor or no access to public transport has repeatedly been highlighted as a widespread barrier to participation by researchers in diverse contexts, including but not limited to Glass *et al* (1997) and Whiteneck *et al* (2004). Confirming earlier evidence regarding transportation and access, the participants here identified inaccessible busses and mini-busses/combis in and around Gaborone;

extremely expensive private car transport; as well as driver attitudes (not wanting to load and/or charging extra for a wheelchair) as inhibiting them from taking part in social life.

Attitudinal barriers manifest in different ways: As already noted earlier by Löfvenmark *et al* (2016), participants here also reported devaluing attitudes and public stigma, highlighting government officials' attitudes which contributed to their dissatisfaction with the services they received. Participants indicated that there were hardly any persons with disabilities in government departments, which they felt could contribute to their needs being misunderstood and that the government could assist them better if they were represented by more persons with disabilities. Official attitude barriers also translated into public attitude barriers for example where some participants complained about lack of awareness or consideration where able bodied community members parked, blocking their access points in public places.

Policy, decision making and service delivery barriers: Participants felt that accessibility issues might be due to decision makers' lack of consultation with persons with disability. Furthermore, they felt misrepresented by those *without* disability who, though pushing issues of persons with disability, tend to overlook or not understand access issues fully. WHO (2013) notes that quality of life of persons with SCI in low-income countries, and in many middle-income countries including Botswana, was more dependent on factors such as how much their environments are facilitating suitable resources and services available, supportive relationships available *and/or their inclusion in the community and in decision making*. In line with this, participants described how persons with disabilities were not being recognised and not included in consultations with regards to services and adaptations which should aid accessibility (- hence improving participation). They complained about non-recognition and not being given a voice in gatherings where they were specifically invited to voice out their challenges. With regards to recognition, interviewed participants pointed out that in most cases, their challenges are conveyed by able representative persons and not by persons with disabilities.

Social barriers and isolation by the community was voiced out in this study in examples of social interactions where community members long familiar with them, did not address them but instead communicated with their caregivers in their presence. Löfvenmark *et al* (2016) highlighted in their study that, the society's effect/impact was based on devaluing attitudes which

contributed towards barriers which persons with SCI were facing and also indicated that in the past, families preferred to hide persons with disabilities in the backyard houses which was not the case in the findings of the current study.

Financial barriers included the double problem of loss of employment and lack of insurance and these have been identified earlier as a barrier to participation (Silver et al 2012). Furthermore, Boschen et al (2003) pointed out that transport and insurance challenges were often identified as preventing persons with SCI to access needed medical and rehabilitation services, thus having adverse effects on the physical impairment etc.

Persons with SCI caused by road traffic accidents in Botswana are either covered fully or have a limited cover from the Motor Vehicle Accident (MVA) fund and both accounts are governed by policies. They are insured depending on the aetiology of their injury therefore some of them are not insured by the MVA fund but are dependent on the government to provide for their medical and technical aids needs. Again, with those insured by MVA Fund are covered differently depending on the police statement which will state the details of cause of the accident, who was at fault and who did not use safety measures during the accident. This determines the extent of the insurance coverage. As mentioned during the interviews, persons with SCI with causes other than road traffic accidents are forced to wait for technical aids for a long time. This was described as due to the government catering for all needs of persons with and without disabilities.

Löfvenmark *et al* (2016) wrote about the family assisting once the social welfare fails. In the current study, interviewed participants also indicated that they had to ask for donations and/ or to go to banks for a loan should they be faced with such. However, participants understood that assistance would have come from the central government and again would not be termed having failed. Some participants also mentioned reasons such as limited government budget and responsibilities etc. which could cause the delay in providing technical aids. With regards to the government, some participants acknowledged government's hard work in trying to provide services despite its large catchment areas of care which it has to fulfil.

Even those still or again engaged in economic activities voiced out financial concerns such as the costs of maintaining their technical aids, other disability-related costs etc. as well as taking care of their families. SCI is costly, with expenses incurred from day one of the injury throughout person's life ranging from, acute hospitalization, use of transport, medical equipment, consumable supplies, personal assistance, home and vehicle adaptations (Priebe et al. 2007; WHO 2013). As Löfvenmark et al (2016) had indicated, family played a major role in supporting persons with SCI when the social welfare system had failed to do so. The participants here had not yet registered for the recently introduced disability allowance [Stop Press: Monitoring, evaluation and research of the system is keenly awaited]. Some participants had mentioned taking loans in order to survive, while others had mentioned being unemployed and dependent on the family, government and charity (as they do not have educational background and therefore jobs to earn a salary).

Employment barriers included problems of re-integration – a widespread problem. As far afield as in Thailand, people with SCI do not return to their employment due to negative stigma with regards to being productive so they seek other means of income generation such as being lottery ticket vendors (Suttiwong *et al* 2015). In Botswana, for those unemployed and with disability including SCI, the government is providing alternate income generating activities (e.g. backyard gardening) as a way to eradicate poverty. As for those participants who had previous employment, there is no binding document/policy in Botswana to encourage return to work as return to previous employment is based on being understanding and being compassionate. Also most workplaces are not adapted to accommodate persons using wheelchairs.

Efforts to return to work, according to one participant here, injured at the time he was working, was reported unsatisfactory as he felt under-utilized yet having capabilities to perform an alternative job. Another participant, previously doing a physically demanding job, found himself not returned to work though reported having normal upper body function and again there was no alternative employment negotiated with him.

Thus the widespread situation already confirmed by Priebe et al (2007) was seen again here, that is; that persons with traumatic SCI are faced with complex unemployment challenges that need more direct and evidence-based engagement by employers and other stakeholders.

Barriers to education and un- or under-employment are related; so are access to education and subsequent employment opportunities (WHO 2013). This was confirmed in the Botswana context when Löfvenmark et al (2016), identified that for informants with SCI and with a high level of education, this worked to their advantage to continue with their previous employment. In the current study some participants had indeed blamed the SCI to have contributed to their low levels of educational qualifications and poor employment opportunities. For one participant, the SCI had interrupted his education and made it difficult to return to school. This was reported to have occurred before the current model of SCI rehabilitation was applied in Botswana, and needs further exploration.

Facilitators:

The Theme 5 header (*'I won't sleep on an empty stomach when they are around'*) typified the facilitating role of family support and confirmed what earlier studies had found in diverse contexts (Angel et al 2009; Chang et al 2005; Kennedy et al 2006; 2010). However, it needs to be highlighted that while the value of family support is indeed a predominant facilitating factor, instances were described here of community and family members, anxious and worried about the person with SCI, resulting in them being too assistive to them (WHO 1996). In this regard, close family members were described in two ways. On the one hand, family were being overprotective and hindering activity and participation, hoping to prevent their loved one with a SCI from being injured in the due course; yet killing the spirit of being functionally independent. On the other hand, family was described to offer unconditional support to persons with traumatic SCI and had always continued the respect they gave them while they were not injured, giving them the chance to be independent. This complements the findings of Löfvenmark et al (2016), indicating that family support was crucial to their interviewed informants for reasons such as care-giving and emotional support.

Friends – described as being those people who did not give up on them - were strongly appreciated by participants here. This adds to the finding of Löfvenmark et al (2016), where their informants stated feeling normal when they were treated with a sense acceptance by their friends.

Community attitudes were appreciated by participants and the Batswana people - as a nation - were praised as a compassionate and loving community, willing to offer any kind of help to persons with disabilities, including those with SCI. Other views on public attitudes reflected a possible lack of public knowledge and experience of well-rehabilitated persons with SCI and their potentials and capabilities (as shown in the responses about community members seeing them out and about and concluding that they must then be ‘faking disability’).

Informants in Löfvenmark et al (2016) study mentioned that church members were the most understanding people. Participants interviewed here, voiced out that being mentored in church was giving them hope in life, including discussions on ways to deal with difficult situations.

Finally, the neuro-rehabilitation received at the SCI rehabilitation unit should not be underestimated as a facilitator in supporting participants’ ability in life management, functional performance and community re-integration.

Individual coping strategies

The third objective of the study was to explore and describe the individual coping strategies of the persons with SCI. These included personal faith and (self-) acceptance, recognition of one’s own capabilities, determination and hard work and the fulfilment of roles and responsibilities as active family members and citizens. The overriding, positive coping sentiment was succinctly expressed in one participant’s response which became the heading for Theme 6: *I believe there is nothing that can be difficult for me.*

Faith and spirituality is recognised to play an important part in the lives of persons with disabilities, including acquired disabilities such as traumatic SCI (WHO 2013). Interviewed participants here indicated that ‘*giving their lives to God*’ was one of the ways that assisted them in accepting their injuries. Löfvenmark et al (2016) observed that Christianity and traditional religions were mentioned to be a general part of life in Botswana, while participants in the current study only talked of the one true God as their comforter in dealing with their injuries. Being spiritual allowed participants to function well in their lives as they believed it was God’s plans for them and they did not feel being punished but indicated spirituality as a coping strategy unlike in study conducted by (Löfvenmark et al 2016) where informants felt cursed.

Acceptance was a recurring topic and some participants mentioned to have accepted their injury which helps them to move forward in their life. Others mentioned not being able to think forward in their life. Acceptance or satisfaction with life for persons with SCI is documented when they are taking part in productive activities such as working, leisure and education (Cushman & Scherer 2002). These activities associated with life satisfaction for persons with SCI were further emphasized to be associated with community reintegration hence improved quality of life (Crewe & Krause 2009; Fuhrer et al 1992).

Participants indicated the importance of continued identification with their social roles (husband, father, brother, son etc.). The *ability* to perform related tasks and actions, such as being able to fetch water, to fetch woods to make fire, cooking, pushing wheelchair etc. were ascribed to hard work and determination. Statements indicating participant's determination and capabilities were generally linked to the way in which individuals were looking at life.

Responses also indicated that their determination influenced their functional rehabilitation outcome. As concluded by Suttiwong et al (2015), the main aim of rehabilitation is bringing close to normal their *desire* to participate in community. Participants rehabilitated at the national SCI unit were taken through active and intense rehabilitation; training them to live with their injuries through participating in activities of daily living and developing some sort of daily routine for themselves. Some participants had shown some ability to perform activities such as their morning routines including bathing, dressing, transfers and/or being able to push their wheelchair themselves in the community with occasional help needed due to environmental challenges, as also reported previously (Hammell 2007; Manns & Chad 2001) .

Earlier evidence included the observation that those who complained of environmental factors were the ones who seldom go out while those who are outgoing would have found a way to go about environmental factors (Suttiwong et al 2015). This was expressed here through participants' recognition of their often newly identified capabilities, determination and hard work.

As noted earlier, participation involves factors such as choice, control and making use of opportunities available to them (Hammel et al 2008; Heinemann et al 2013). Some participants

in the study indicated abilities and interests to learn and perform activities of daily living (including tasks for their family) and expressed happiness, a sense of achievement and pride in themselves.

Successful community reintegration in terms of the ICF (WHO 2001), includes participation in family and community life; taking an active and contributing part in normal roles and responsibilities (Carpenter et al 2007); or in other words, activities of daily living and social roles acknowledged by the socio cultural setting (Noreau & Fougere 2000). While the activity limitations of SCI were realistically described by participants, examples of real participation were also given.

The findings of this small scale study confirm a diverse range of earlier evidence, both in different and in similar contexts, and have added specifics in terms of the experiences of patients' with traumatic SCI post-discharge in Botswana. The findings also confirm the dynamic interaction between each component and ***all*** of the other components in the ICF framework (WHO 2001). The individually different lived experience of each participant, after returning to their home and community after discharge, was indeed affected by the impairment, activity limitations, and environmental as well as personal factors – as depicted in the personally adapted illustration of the ICF in Figure 2.

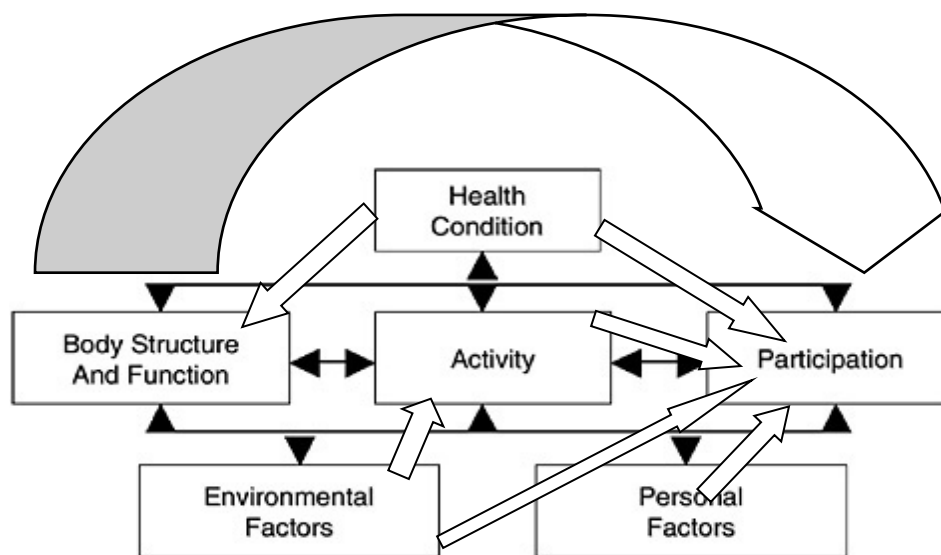


Figure 2: A reflective visualisation of the ICF as applied in this study, to emphasise how all factors influence participation.

Limitations of the study

While every effort was made to avoid study *weaknesses*, unavoidable *limitations* of this small scale study for degree purposes included:

- Logistical limitations: finding and arranging home visit interviews with past patients was severely affected by the lack of up-to-date contact details for some; i.e. cell/mobile numbers being no longer valid.
- Time and distance limitations; it was not possible to do second or third follow up visits to get more or richer data; and it was only possible to include participants from Gaborone and the surrounding areas within a 100km radius.
- Much is lost in translation and due care was taken with carrying out the interviews in the participant's language of choice (Setswana or English). However, those done in Setswana had to be translated into English and some of the idiomatic and semantic richness of the participants' responses may have been lost.

Strength of the study

As an indigenous person from Botswana and a Setswana mother-tongue speaker myself, my positioning as the researcher and my language competence as the interviewer helped in gaining the participants' trust and confidence in sharing personal life experiences, as described by other indigenous researchers earlier (Clark et al 2011; Mihesuah, 2004). Indigenous researchers can reduce the previously observed power- imbalances in research by 'first world' researchers in 'third world' countries (Owusu-Ansah & Mji 2013; Swartz, 2014).

Implications and Recommendations

A widespread gap between research evidence and the implementation of strategies that meet the real needs of people 'on the ground' has been identified earlier (Hartley & Wirz, 2002; Kachaje et al 2014). Furthermore, Hartley and Wirz (2002: 1553) confirm that this gap between evidence and implementation may be reduced by researchers specifying particular stakeholder groups when stating the implications of their research findings; and formulating practical and

constructive recommendations. The following four stakeholder groups were thus identified; with recommendations to them synthesised from the responses of the study participants themselves:

- Other persons with SCI and their families can:
 - initiate the formation of community based support groups to empower themselves with peer support and role modelling; and strengthen their voice in matters of advocacy for themselves and others.
- Health and rehabilitation professionals can:
 - advocate for (and implement) more home visits and family consultations to increase the responsiveness of rehabilitation services in preparing persons with traumatic SCI better for community re-integration.
- Decision makers can:
 - include more persons with disabilities (including persons with SCI) at *all* levels of decision making (from the National Government to service delivery end points)
 - promote and implement disability advocacy for persons with SCI and/or with other disabilities, for example; to include more public education on their capabilities and to provide opportunities for their participation as active (not just nominal) citizens.
- Future researchers can:
 - use the findings to generate further research questions, to implement bigger studies with more participants and explore more specific needs of persons with SCI in Botswana to inform decision makers and service delivery.
 - collaborate with indigenous researchers and those interested in becoming researchers, to be able to explore the lived experiences of persons with SCI (and other groupings) more from an insider perspective.

Conclusion

This small-scale study achieved the planned purpose of presenting some of the life experiences of persons with a traumatic spinal cord injury (SCI), after returning to their homes, as described by the participants themselves. Six participants (two in the pilot and four in the main study) were interviewed in their homes in and around Gaborone, Botswana; with follow-up phone interviews

implemented to supplement and verify the earlier home-based interviews. Thematic content analysis of the participants' responses led to the identification of six themes which in turn were synthesised to a series of practical implications and constructive recommendations to (a) help and empower other patients; (b) assist health and rehabilitation professionals in preparing persons with SCI better for community re-integration; (c) inform decision makers at diverse levels in identifying issues that need to be addressed to make service delivery more responsive to real needs and to (d) help generate future research questions.

In conclusion, there is a need for more, and deeper, direct engagement with, and decisive responses to, the needs and contributions of persons with SCI who have returned to their homes and are endeavouring to re-integrate into their diverse contexts.

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(Appendices in order/sequence as mentioned in text)

Appendix A: Interview Guide (English)

SEMI-STRUCTURED INTERVIEW: GUIDING QUESTIONS

(applied flexibly depending on detail and sequence of participant's respective responses)

1. Good morning/afternoon. How are you?
2. How are things going?
3. Can you tell me about your injury?
4. How did you get injured?
5. How long have you been injured?
6. How did the injury affect/ impact on your life?
7. How did you live your life before you were injured?
8. What were your interests then?
9. Tell me/describe your daily life after injury?
10. How do you manage with your everyday life?
11. Are you able to access your home and community with the use of wheelchair?
12. How do you feel people treat you at home and the community?
13. What are your sources of income?
14. Is having an insurance making any difference in your life? And or how is not having insurance affecting your life?
15. How do you think of quality of your life after the injury?
 - (a). What factors contribute to making your life positive?
 - (b). What factors/ what makes your life negative?
16. What are your roles and contributions in your family since you were injured?
17. Do you see yourself as disabled?
18. What are your views on disability?

Appendix B: Interview Guide (Setswana)

DIPOTSO TSA DIPUISANYO: SETLHOGO: BOLENG JWA BOTSHELO JWA BATHO BA BA NANG LE KGOBALO YA MONYETSANA E E FELETSENG MO GABORONE LE MAFELO A A MABAPI.

1. Dumelang! O tsoga jang?
2. Botshelo bo tsamaya jang?
3. A o ka mpolelela ka kgobalo ya gago.
4. Go tlile jang gore o bone kgobala?
5. Go lebaka le le kae, o ntse o golafetse?
6. Kgobalo e amile kana e fetotse botshelo jwa gago ka tsela e ntseng jang?
7. ne o tshela botshelo jwa gago jang pele fa o gobala?
8. Dikeletso tsa gago ene ele eng ka nak eo?
9. Ke kopa gore o mpolelele kana o tlhalose gore botshelo jwa gago jwa letsatsi le letsatsi bo ntse jang morago ga kgobalo?
10. kgona jang botselo jwa gago letsatsi le letsatsi?
11. A o kgona go dirisa kolotsana (wheelchair) ya gago mo lapeng le mo motseng?
12. akanya gore batho ba go tshwara ka mofuta ofe fa o le mo lwapeng kana mo gae?
13. Ke dife ditsela tse di go thusang go nna le madi/kgotsa go bona madi?
14. A go nna le dithuso tsa madi (insurance) go fetola botshelo jwa gago ka tsela nngwe?
Kana go tlhoka dithuso tsa madi (insurance) go ama jang botshelo jwa gago?
15. akanya gore boleng jwa botshelo jwa gago, bo ntse jang morago ga kgobalo?
 - (a). Ke mabaka afe, a a thusang bootshelo jwa gago go nna botoka?
 - (b). Ke mabaka afe/ ke eng se se koafatsang botshelo jwa gago?
16. Tiro ya gago ke eng mo lwapeng, le gore o thusa jang mo lwapeng sale o gobala?
17. A o ipona o le segole?
18. Maikutlo a gago ke afe ka dikgang tsa bona le bogole?

Appendix C: Information and Consent form (English)

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT:

Quality of life of persons with complete traumatic spinal cord injuries in Gaborone and surrounding areas: A qualitative Enquiry.

REFERENCE NUMBER: S14/10/232

RESEARCHER: Beauty Kwadiba

Researcher's address: P.O. Box 53675, Broadhurst, Gaborone

Researcher's contact numbers: 7280 5334 / 7370 7624

Dear Participant,

My name is **Beauty Kwadiba** and I am a Masters Student enrolled at Stellenbosch University. You are kindly invited to take part in a research project that I am doing as part of a Masters in Human Rehabilitation. The aim of my study is to explore the quality of life of persons with Traumatic Spinal Cord Injury living in Gaborone and surrounding areas. You are asked to take some time to read the information which will explain the project. Please feel free to ask me any questions about this project regarding anything that you might not understand. Your understanding of what the research project entails is highly appreciated as you will have an idea of how you could be involved.

Please note that it is not forced and you are free to refuse to take part. If you say no, this will not affect you at all. You are also free to pull out from the study at any point, even if you at first agreed to take part.

To ensure that the study has followed right procedure, this study has been checked and approved by the Health Research Ethics Committee (HREC) at Stellenbosch University. The study will be done according to national and international ethical guidelines and principles, including those of the international Declaration of Helsinki October 2008. Permission was also given by the Ministry of Health of Botswana and Princess Marina Hospital Ethics Committee to make sure that the study follows ethical principles, for your protection.

INFORMATION REGARDING RESEARCH STUDY

The study is focusing on the daily life experiences of persons with spinal cord injuries. I chose this topic after learning the challenges experienced by persons with traumatic spinal cord injuries

such as expensive technical aids; the lack of or limited insurances and issues of secondary complications such as pressure wounds and bladder complications just to name a few. I hope that the research will help persons with spinal cord injuries by helping others to understand how they live in their everyday life in their communities. I hope that the research will be educational to the government and Insurance Organizations such Motor Vehicle Accident Fund and will help to develop and/ or change existing policies to help persons with spinal cord injuries in Botswana.

Why are you invited to participate in the study?

The study is a qualitative study and will be done with seven participants with traumatic spinal cord injuries residing in Gaborone and surrounding areas in Botswana of ages from 18 years to 55 years old. Participants will be knowingly selected. You are invited to take part in the study because it is likely that you can give helpful information for the research study.

Risks involved in the study

The study does not involve any experimentation or treatment. It will involve talking about past or current life experiences which might be emotional to some participants. If you become emotional, I will make sure that you are supported, by me or a more qualified colleague.

Your expectations

You will be asked questions face to face by me (the researcher) or my research assistant. All interviews will be recorded. During the session, I will also take only contextual/ environmental photos to help me with in writing in-depth field notes.

Ethical Consideration

Any data taken during the interviews, the voice recorder and contextual/ environments photos with a camera will be kept safely at work under a lock and a key. Contextual/environmental photos to assist in writing detailed field notes/observational notes. We will not use your real name in the reports of the research study, in order to protect your privacy.

Who will have access to your information?

I, the researcher will be conducting the interviews and only I and a research assistant will have access to the information about you. My research supervisors will also have access to research information since there are guiding me to do a proper and a high quality research and they are Co-Researchers. Photos and information gathered will be kept at my work office, locked away safely during research process but will be kept in a document bank. The public will have access

to the completed research study, but your name and personal details will not be in it to protect your privacy.

Will you receive payment for taking part in the study?

No, there will not be any form of payment for you. There will also not be any cost/expense for you because all interviews will be conducted in the home of the participant, and the study does not involve you travelling and or being treated.

In the event of feeling upset by the questions, you will have emotional support as I (the researcher) am an Occupational Therapist, with experience in counselling. There will also be an arrangement with a social worker or psychologist to assist you further if you need it and you will not be asked to pay for anything. You will be contacted telephonically should a need arise in order to be assist promptly.

If you have any questions at any time:

Please contact me, Beauty Kwadiba at 72805334/73707624 or Princess Marina hospital Ethics Committee at 3621400. You may also contact the Stellenbosch University Health Research Ethics Committee on 0027 21 938 9207 if you have any questions, concerns or complaints that have not been answered or solved by me, the researcher.

Yours sincerely

Beauty Kwadiba

(Researcher)

Declaration by participant

By signing below, I agree to take part in a research study, 'Quality of life of persons with complete traumatic spinal cord injuries in Gaborone and surroundings areas.'

I declare that:

- I have read the attached information leaflet and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **NOT FORCED** and I have not been put under pressure to take part.

- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.
-

Signed at (*place*) On (*date*) 2015.

.....

Signature of participant

Declaration by investigator

I (*name*) declare that:

- I had explained the information with regard to research study in this document to (Name of a Participant).
- I encouraged him/her to ask questions and take enough time to answer them.
- I am pleased that he/she understood all details of the research, as discussed above.
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*)
- I will provide onsite emotional support immediately, if required.
- I will notify social worker and or psychology department immediately should a need arise.

Signed at (*place*) on (*date*) 2015.

.....

Signature of investigator

.....

Signature of witness

Declaration by Research Assistant

I (*name*) declare that:

I will ensure that I will follow all guidelines to keep information gathered by the researcher confidentially.

Signed at (*place*) on (*date*) 2015.

.....

Signature of Research Assistant

.....

Signature of witness

Appendix D: Information and Consent form (Setswana)

PAMPIRI YA MO TSAYA KAROLO YA DITHUTO MABAPI LE DIPATLISISO LE DITUMALANO TSA GA MO TSAYA KAROLO SETLHOGO SA DITLHOTLHOMISO

Boleng jwa botshelo jwa batho ba ba nang le kgobalo ya monyetsana e e feletseng mo Gaborone le mafelo a a mabapi.

REFERENCE NUMBER: S14/10/232

RESEARCHER: Beauty Kwadiba

Researcher's address: P.O. Box 53675, Broadhurst, Gaborone

Megala ya Motlhotlhomisi: 7280 5334 / 7370 7624

Go Motsaa Karolo,

Ke bidiwa **Beauty Kwadiba**, ke moithuti mogolo wa dithuto tsa Masters (Digarata) mo Human Rehabilitation Studies kwa Stellenbosch University. O kopiwa ka boikokobetso go tsaya karolo mo dipatlisisong tse ke di dirang e le karolo ya dithuto tse di kgolwane tsa Digarata tse di itebaganteng le Human Rehabilitation Studies. Dipatlisiso tse, di itebagantse le boleng jwa botshelo jwa batho ba ba nang le kgobalo ya monyetsana e e feletseng mo Gaborone le mafelo a a mo tikologong. .

O kopiwa ka boikokobetso gore o iphe nako go boisa dintlha tse di kwadilweng mo pampiring e o e neetsweng gore e go tlhalosetse ka botlalo mabapi le dipatlisiso tse di dirwang. O kopiwa gape gore o tshosologe go ka botsa dipotso mo dikgannyeng tse o ka tswang o sa di ditlhaloganye mabapi le dipatlisiso tse di dirwang. O gakololwa gore o tlhaloganye gore go botlhokwa thata gore o tlhaloganye dipatlisiso tse di dirwang ka gore o tla kgona go thusa mo go tshwanetseng ka patlo maikutlo ka dipatlisiso..

Malebang le go tsaya karolo ga gago, o kopiwa go ela tlhoko gore ga o pateletswe go ka tsaya karolo. O le mo tsaya karolo, lemoga gore o a letlelesega go ka fetola maikutlo a gago mabapi le botsaa karolo mo dipatlisisong.

O gakololwa gore, go gana go tsaya karolo ga gago mo dipatlisisong ga go kitla go go ama ka mokgwa ope fela le gore fa o fetola tshwetso ka go tsaa karolo o a letlelesega gore o seka wa tswelele ka go tsaya karolo mo dipatlisisong le fa o ne o dumetse kwa tshimologong.

Go netefatsa fa dipatlisiso di setse morago melao ya dipatlisiso, kopo ya go dira dipatlisiso e ne ya isiwa kwa komiting ya **Health Research Ethics Committee (HREC) kwa Stellenbosch University** mme ya letlelelwa ke komiti ya dipatlisiso ya Stellenbosch University. Se se rurifatsa fa dipatlisiso di tla dirwa ka mokgwa o o setseng melao morago go balelwa le melao ya dichabachaba ya Declaration of Helsinki October 2008.

Teseletso e nngwe e ne ya kopiwa ko go ba komiti ee rurifatsang fa melao ya go dira dipatlisiso e salwa morago bone ele ba lephata la botsogo mo Botswana (Ministry of Health of Botswana) le ba komiti ya dipatlisiso ya sepatela se segolwane sa Princess Marina Hospital. Se se netefatsa ka boammaaruri fa dipatlisiso tse di dirwang di setse morago ditsetlana tsa melao go itsa kgotsa go fokotsa borai jo dipatlisiso di ka bo bakang mo go wena o le mo tsaya karolo.

Tshedimosetso mabapi le dipatlisiso

Dipatlisiso di itebagantse le go tlhotlhomisa ka fa batho ba ba nang le kgobalo ya monyetsana ba tshelang ka teng mo Gaborone le mafelo a a mo tikologong. Setlhogo sa dipatlisiso se ne sa tlhomiwa morago ga go lemoga dikgwetlho tse di farologanyeng tsa batho ba ba nang le kgobalo ya monyetsana jaaka ditlhwatlhwa tse di kwa godimo tsa didirisiwa, letlhoko le tlhelo ya dithuso tsa madi, ditlamorago tsa kgobalo ya monyetsana jaaka go tswa dintho le tsa pereko ya setlha le mala, ke fela ke nankola di se kae.

Dipatlisiso tse di dirwang di tla tswela mosola thata batho ba ba nang le kgobalo ya monyetsana ka gore e tla lemotsha sechaba ka kakaretso ka fa ba tshelang botshelo jwa bone jwa letsatsi le letsatsi fa ba le kwa magaeng a bone. Ka thulaganyo ya mofuta o, dipatlisiso tse di tla sedimosetsa ba lephata la ga Goramente le lekalana la dithuso tsa madi la batho ba dikotsi tsa tsela la Motor Vehicle Accident Fund ka mathata a batho ba kgobalo ya monyetsana le ka fa ba tshelang ka teng. Mme dipatlisiso di tla thusa gape ka go simolola kgotsa go fetola ditsetlana tsa melao tse di supang ka fa batho ba kgobalo ya monyetsana le ba bangwe ka kakaretso ka fa ba tshwanetseng go ka thuswa ka teng mo lefatsheng la Botswana. Dipatlisiso di tla thusa ka go tokafatsa tsamaiso ya ditirelo tse di neelwang batho ba ba nang le kgobalo ya monyetsana le ba bangwe ba ba nang le kgobalo ya monyetsana e e sa bakiwang ke kgobalo fa ba le kwa malwapeng a bone mo Botswana.

Ke ka go reng o laleditswe go tsaya karolo mo dipatlisong?

Dipatlisiso tse, ke tsa patlo maikutlo le gore di tlaabo di akaretsa ba tsaya karolo ba le basupa ba ba dingwaga go simolola ka tse lesome le boferabobedi go ya kwa go tse di masome a botlhano le

botlhano. Dipatlisiso di akaretsa ba tsaya karolo ba ba nang le kgobalo ya monyetsana mo Gaborone le mafelo a a mabapi.

Batsaa karolo ba tla tlhophiwa ka go itsiwe gore batla neela tshedimoso ka fa ba tshelang ka teng. O lalediwa go tsaya karolo mo dipatlisisong tse, ka gore o tla neela dikitso tse di botlhokwa mo dipatlisisong.

Bodiphatsa jo bo amanngwang le dipatlisiso

Ga go na ditekeletso kana kalafi e e tla dirwanng mo dipatlisisong tse. Dipatlisiso di tla akaretsa dikgang tsa go bua ka mekgwa ee fitileng le ya segompiano e le ya go tshela ka kgobalo ya monyetsana mo go, ka nna ga baka kgoberego ya maikutlo.

Ditsholofelo tsa gago

Jaaka go sa tswa go buiwa, dipatlisiso tse ke tsa patlo maikutlo a a nang le boleng, jaanong o tlaabo o botswa dipotso ke motlhotlhomisi mme mothusi wa gagwe ene a tseye dinepe tsa tikologo. Dipuisanyo tsotlhe di tlaabo di kapiwa mantswe. Go tla tsewa dinepe tsa tikologo mo lwapeng go thusa mo go kwaleng dintlha tse motlhotlhomisi a gakologelwang gore o di bone e bile le go thusa go kwala mabaka a a tsepameng e bile a a feletseng go supa ka fa batho ba kgobalo ya monyetsana batshelang ka teng.

Dipuisanyo tsa dipatlisiso tsotlhe di tlaabo di direlwa kwa malwapeng a baba tsayang karolo mo dipatlisisong ba na le kgobalo ya monyetana e e feletseng, jalo o kopiwa ka boikokobetso go neela tseletso gore dipuisanyo tsa dipatlisiso di direlwe kwa lwapeng la gago.

Kelethoko ya melao ya pabalesego (Ethical Consideration)

Dintlha tse di tlaabong di kgobokantswe tsa dipatlisiso ka dipuisanyo, sekapa mantswe le sekapa ditshwantsho di tla a bolokelwa kwa tirong mo ofising, mo teng ga koboto e e lotlelwang. Kgatiso ya dintlha go tswa mo sekapeng mantswe go ya mo mokwalong, e tla direlwa kwa ga me, ke le motlhotlhomisi e le tsela ya gore ke nne le nako e ntsi go buisa dintlha, mme di tla busediwa kwa lefelong le le babalesgileng kwa tirong mo kobotong e e lotlelwang fa ke feditse ka puisanyo nngwe le nngwe.

O tlaabo o neelwa leina le eseng la boammaaruri le le kgethilweng ke wena pele ga di puisanyo di siolola. Leina le, ke lone le le tlaabong le dirisiwa mo go kwaleng dipatlisiso tse di feletseng.

Ke mang yo o tla nnang le kamano le dintlha kana tshedimosetso eo tla e neelang?

Motlhotlhomisi o tlaabo a dira dipuisanyo le wena ka dipatlisiso. Motlhotlhomisi le mothusi wa gagwe ke bone ba batla nnang le tseletso le dintlha kana tshedimosetso tse e leng gone di sa

tswa go kgobokanngwa le gore dintlha di tla bolokelwa kwa tirong mo kobotong e e lotlelwang mo ofising. Motlhotlhomisi mogolwane ebile e le ene yo o beileng leitlho gore dithotlhomiso di dirwa sentle, le ene o tla nna le seabe mo ditlhotlhomisong tse di sa tswang go dirwa le wena. O tlaabo o neetswe leina le eseng la boammaaruri ka nako ya dipuisanyo le kgatiso ka gore sechaba ka kakaretso se tla buisa dipatlisiao tse di feletseng.

A go tsaya karolo go a duelelwa?

O itsisiwe fa go sena dituelo dipe tse o tla di neelwang gore o tsaya karolo mo dipatlisong ka mabaka a gore dipuisanyo tsa dipatlisiso di tlaabo di direlwa kwa lwapeng la gago le gore fa godimo ga moo, ga o na go solofelwa gore o nne le meepele. Dipatlisiso tse di dirwang ga di na kalafi kana ditekeletso tsa mofuta ope o o tla dirwang. O le motsaya karolo mo dipatlisong, o lemotshiwa fa o kitla o nna le ditshenyegelo ka gope mo karolong ya dipuisanyo go kgobokanya patlo maikutlo. O tla bona tshegetso ya tshidilo maikutlo fa go ka diragala gore go nne le seemo se se ka go kgoberang maikutlo ka ka nako ya dipuisanyo ka gore motlhotlhomisi ke Occupational Therapist, o ka kgona go go thusa o santse o emetse thuso ya tshidilo maikutlo. Go tla nna le thulaganyo ya maphatla a tshidilo maikutlo jaaka la bo Mmaboipelego le la Tshidilo Maikutlo (Psychology) mme, o tla seke o duela sepe.

Ga ona le dipotso ka nako yotlhe

O kopiwa go ikgolaganya le Beauty Kwadiba mo nomoreng ya 3621418/ 72805334/73707624 kgotsa o ikopanye le ba Princess Marina hospital Ethics Committee at 3621400. O ka ikopanya le ba Stellenbosch University Health Research Ethics Committee on 0027 21 938 9207 kgotsa Ms Martha Geiger, ele Motlhotlhomisi yo mogolwane yo mogwe mo dinomoreng tsa Phone; (+27) 21 911 0365 Mobile; (+27) 82 440 8713 ka kgang e nngwe le e nngwe kana o na le ngongorego e nka tswang ke sa kgona go e ama kgotsa go e araba go go kgotsofatsang.

Ke le wetsho

Beauty Kwadiba

(Researcher)

Maipolelo a Motsaya Karolo

Ka go baa monwana kwa tlase, nna ke dumelana le gore ke tsee karorolo mo dipatlisong tsa boleng jwa botshelo jwa batho ba ba nang le kgobalo ya monyetsana mo Botswana.

Ke bolela gore:

- Ke buisitse pampiri e e kgomareditsweng ya tshedimosetso le gore e kwadilwe ka puo e e motlhofo e bile ke e tlhaloganya ya botlalo.
- Ke nnile le sebaka sa go botsa dipotso, mme dipotso tsame tsotlhe di arabilwe mo go kgosofatsang
- Ke tlhaloganya gore go tsaya karolo go tswa mo go nna e bile ga ke a patelediwa go tsaya karolo.
- Ke na le gore nka tlhopha go tsaya tshwetso ya go tlogela dipatlisiso ka nako e nngwe le nngwe go sena kotlhao kana lethoo ka tsela epe fela.
- Go ka diragala gore ke kopiwe go tlogela dipatlisiso pele di isi di fele, fa e le gore motlhotlhomisi o akanya gore go dira jalo go ka nthusu, kgotsa fa ke sa sale morago lenaneo la dipatlisiso jaaka re dumalane.

E beilwe monwana kwa.....ka di..... 2015

Monwana wa mo tsaya karolo/ kana motlhokomedi wa gagwe.....

Appendix E: Photograph - information leaflet and consent form (English)

TITLE OF THE RESEARCH PROJECT:

Quality of life of persons with complete traumatic spinal cord injuries in Gaborone and surrounding areas; A qualitative Enquiry.

REFERENCE NUMBER: S14/10/232

RESEARCHER: Beauty Kwadiba

Researcher's address: P.O. Box 53675, Broadhurst, Gaborone

Researcher's contact numbers: 7280 5334 / 7370 7624

Thank you for agreeing to consider taking part in this study.

As part of this research study, it will help if some environmental/contextual photos (e.g. of buildings, doorways, pathways, steps, terrain etc.) can be captured in order to assist during compilation of detailed field notes/observational notes as one form of collecting information. These photographs will be used for the purpose of the study only, and will not be made public in any way (e.g. in magazines, on TV or in newspapers). Any contextual/ environmental photographs will be stored safely in document bank until they are no longer needed after ten years and then destroyed. Your privacy will be protected at all times, and as a researcher, I assure you that I will do all I can to keep the information safe. You are kindly asked to give your permission so that researcher and research assist capture only your contextual/environmental photos.

Declaration by participant

I..... do / do not give permission for contextual/environmental photographs of my home environment to be captured for the purpose of this research. I understand that the photos will be used only to help the researcher to see and analyse the information needed for this study and that the contextual/ environmental photos will not be made public in any form: either as part of a research presentation or in a paper or electronic publication such as an academic journal or magazine.

Signature

Place signed.....

Date.....

Appendix F: Photograph - information leaflet and consent form (Setswana)

TITLE OF THE RESEARCH PROJECT:

Boleng jwa botshelo jwa batho ba ba nang le kgobalo ya monyetsana e e feletseng mo Gaborone le mafelo a a mabapi.

REFERENCE NUMBER: S14/10/232

Leina la motlhotlhomisi: Beauty Kwadiba

Aterese ya Motlhotlhomisi: P.O. Box 53675, Broadhurst, Gaborone

Megala ya Motlhotlhomisi: 7280 5334 / 7370 7624

Go botlhokwa go itse gore dipotso tse o yang go di botswa ke motlhotlhomisi, di ya go dirisiwa mo dipatlisisong. Go a thusa go itse gore dipatlisiso di ya go akaretsa go tsaya dinepe tsa tikologo ya gago mo lwapeng jalo he, o gakololwa gape gore, go ta kapiwa ditshwantsho tsa tikologo ya gago ya mo lwapeng. Go botlhokwa go go itsi gore ditshwantsho tse di kapilweng di botlhokwa ka gore di tla supa dintlha tsa botlhokwa tse di ka lebalesegang bofefo mo ditlhotlhomisong. O gakololwa gore puiso ya dipatlisiso go ntsha maduo e tla direlwa kwa lwapeng la motlhotlhomisi gore a nne le nako e ntsi ya go buisa patlo maikutlo a dipatlisiso go ntsha maduo le gore e tlaare motlhotlhomisi a fetsa go boisa dipusisanyo fa gare ga gagwe le motsaa karolo, dinepe a di fetolela mo mokwalong a bo a di busediwa kwa ofising go ya go bolokwa mo go babalesegileng.

Ke le Motlhotlhomisi, ke solofetsa gore ntle dira go le go ntsi go diragatsa gore dipusisanyo tsa dipatlisiso di babalesegile.

O kopiwa go neela tetla gore o letlelele motlhotlhomisi le Mothusi wa gagwe go ka kapa ditshwantsho tsa tikologo ya gago.

Maipolelo a Motsaya Karolo

ke le Ke neela motlhotlhomisi tetla ya go tsaya dinepe tsa tikologo ya lefelo le ke nnang mo go lone ka tshedimosetso e a e tlhalositseng gore di ya go dirisiwa e le karolo ya dipatlisiso. Ke tlhaloganya gape gore tshedimosetso ya dinepe e tla bolokelwa mo lefelong le le babalesegileng.

Monwana wa mo tsaya karolo

Lefelo kwa monwana o beilweng.....

Letsatsi.....

Appendix G: Stellenbosch University Health Research Ethics Committee Approval



UNIVERSITEIT•STELLENBOSCH•UNIVERSITY
jou kennisvenoot • your knowledge partner

Approval Notice Response to Modifications- (New Application)

20-Mar-2015
Kwadiba, Beauty B

Ethics Reference #: S14/10/232

Title: Quality of life of persons with complete traumatic spinal cord injuries in Botswana.

Dear Ms Beauty Kwadiba,

The Response to Modifications - (*New Application*) received on 20-Mar-2015, was reviewed by members of Health Research Ethics Committee 1 via Expedited review procedures on 20-Mar-2015 and was approved.
Please note the following information about your approved research protocol:

Protocol Approval Period: 20-Mar-2015 -20-Mar-2016

Please remember to use your protocol number (S14/10/232) on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:

Please note a template of the progress report is obtainable on www.sun.ac.za/rds and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Translation of the consent document to the language applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372

Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Helene Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and documents please visit: www.sun.ac.za/rds

If you have any questions or need further assistance, please contact the HREC office at .

Included Documents:

CV_MGeiger

MOD_Declaration M Geiger

Declaration_BKwadiba

HREC Checklist

Appendix H: Botswana Ministry of Health

TELEPHONE: 363 2766
FAX: 391 0647
TELEGRAMS: RABONGAKA
TELEX: 2818 CARE BD



MINISTRY OF HEALTH
PRIVATE BAG 0038
GABORONE

Republic of Botswana

REF NO: HPDME -13/18/1 Vol. IX (528)

08 September 2015

Health Research and Development Division

Notification of IRB Review: Amendment
Review Type: HRDC

Ms Beauty Kwadiba
P O Box 53675
Gaborone

Dear Ms Kwadiba

AMENDMENT: QUALITY OF LIFE OF PERSONS WITH COMPLETE TRAUMATIC SPINAL CORD INJURIES IN GABORONE AND SURROUNDING AREAS: A QUALITATIVE ENQUIRY

Reference is made to the above mentioned protocol amendment application submitted to the Health Research and Development Committee (HRDC) in the Ministry of Health for review and approval. HRDC have reviewed and approved the following amendment:-

- HRDC Amendment Form dated 28 August 2015
- Amendments Summary
- Research Proposal

Please note that the amendment will expire together with the initial permit.

Amendments

During the approval period, if you propose any change to the protocol such as its funding source, recruiting materials, or consent documents, you must seek HRDC approval before implementing it.

Please summarize the proposed change and the rationale for it in the amendment form available from the Health Research Division Office (HRDD), Office No. 7A 7 or Ministry of Health website: www.moh.gov.bw or can be requested via e-mail from Mr. Kgomo Motlhanka, e-mail address: kgmmotlhanka@gov.bw. In addition submit three copies of an updated version of your original protocol application showing all proposed changes in bold or "track changes".

Reporting

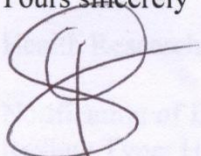
Other events which must be reported promptly in writing to the HRDC include:

- Suspension or termination of the protocol by you or the grantor

- Unexpected problems involving risk to subjects or others
- Adverse events, including unanticipated or anticipated but severe physical harm to subjects.

Do not hesitate to contact us if you have any questions. Thank you for your cooperation and your commitment to the protection of human subjects in research.

Yours sincerely



Dr. K. Seipone

For /Permanent Secretary



Appendix I: Princess Marina Hospital Research Ethics Committee:

PLOT 1836 HOSPITAL WAY

TELEPHONE: 3621400

FAX: 3973776



RE PUBLIC OF BOTSWANA

PRINCESS MARINA HOSPITAL

P. O. BOX 258

GABORONE

BOTSWANA

REF: PMH 5/79(192)

28 September 2015

**Beauty Kwadiba
Stellenbosch University**

Dear Ms Kwadiba

Quality of Life of Persons with Complete Traumatic Spinal Cord Injuries in Gaborone and Surrounding Areas: A Qualitative Enquiry

The Research and Ethics Committee (REC) of Princess Marina Hospital met and discussed your request to amend the study with the aforementioned title. **Full approval** has been granted for the following amendments:

1. Inclusion criteria – “should be injured between 1 year and 15 years”.
2. Correction of the Setswana information leaflet and consent form especially on contextual/environmental photograph.

Please note the following:

1. You must get permission from head of department in the unit that you intend to do your research.
2. You must get informed consent at all times from the people you are using as subjects.
3. You will not change any aspect of your research without permission from the REC.
4. You need to report any unforeseen circumstances including the termination of this study to the REC.
5. You must allow the REC access to the study at anytime for purposes of auditing.
6. This permit is valid for one year; from 24 September 2015 to 23 September 2016.
7. At the end of the study you are requested to give the REC a hard copy and a soft copy of your report.

Wishing you success in your Research.

Sincerely,

A handwritten signature in blue ink, appearing to read 'Gladness O. Tlhomelang'.

Gladness O. Tlhomelang
Secretary Research and Ethics Committee

Appendix J: Princess Marina Hospital Superintendent's Permission

Hospital Superintendent
Princess Marina Hospital
P O Box 258
Gaborone

05 August 2015

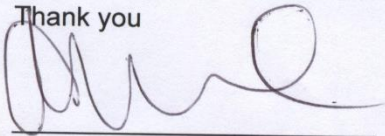
P.O. Box 53675
Broad Hurst
Gaborone

Dear Beauty Kwadiba

**Support granted in conducting a Research Study: Quality of life of Persons
with Spinal Cord Injuries in Gaborone and the Surroundings areas; A
qualitative Enquiry**

Thank you for showing interest in conducting a research study in spinal cord injury and finding it fit to notify me as Hospital Superintend and requesting for my support. This letter serves to inform you that, as Hospital Superintendent and Hospital Management, we grant you our support in ensuring that you to conduct your research study successfully.

Thank you



Dr K. Motumisi
Hospital Superintendent
(Princess Marina Hospital)

Appendix K; Princess Marina Hospital Departmental Permissions:
(a) Orthopaedics Department:

P.O.Box 258
Princess Marina Hospital
Gaborone

03 August 2015

P. O. Box 53675
Broad Hurst
Gaborone

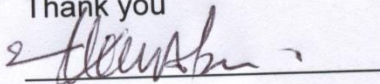
Dear Beauty Kwadiba

**Permission and support granted to conduct a study: Quality of Life of Persons
with Complete Traumatic Spinal Cord Injuries in Gaborone and the
Surrounding areas; A qualitative Enquiry.**

As Head of Orthopaedics I have granted you my support and permission to conduct the above mentioned study on **Quality of Life of Persons with Complete Traumatic Spinal Cord Injuries in Gaborone and the Surrounding areas; A qualitative Enquiry.**

Having granted this permission and my support, I also advice you to follow Ethics guidelines with regards to any changes you wish to indicate in your study in your study according to both ethics committees from Princess Marina Hospital and Ministry of Health. You are also advised that, as Head of Orthopaedics, I and your supervisor have the authority to audit your study at any stage to ensure that ethics guidelines are being followed.

Thank you



Dr Ramabu

Head of Orthopaedics Department

(b) Psychology Department:

P. O. Box 258
Princess Marina Hospital
Gaborone

03 August 2015

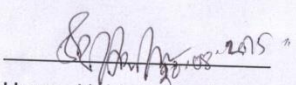
P. O. 53675
Broad Hurst
Gaborone

Dear Beauty Kwadiba

Support granted to assist with Psychology services during conduction of a research study on Quality of Life of Persons with Complete Traumatic Spinal Cord Injuries in Gaborone and the Surrounding areas; A qualitative Enquiry.

I am pleased to inform you that, as Head of the Department in Psychology, I will offer my services to participants taking part in the study mentioned above. I am willing to telephonically provide psychology services as per your request and to make necessary arrangement if a need may be during your conduction of the study.

Thank you for considering Psychology Department to assist in your study if need be.


Umme Habiba Jasmine
Clinical Psychologist